Exploring young people’s management of a dual diagnosis of Type 1 Diabetes and Coeliac Disease: a grounded theory study

By

Nathalie Gray

Thesis submitted for the degree of

Doctorate in Clinical Psychology

University of Leicester

May 2016
Declaration

I confirm that the literature review, research report, and critical appraisal contained in this thesis is my own work. This thesis has not been submitted for any other academic award or to any other institution.
Exploring young people's management of a dual diagnosis of Type 1 Diabetes and Coeliac Disease: a grounded theory study.

Part One: Literature Review

Introduction: The current paper presents a systematic review of the evidence on the psychosocial impact of a dual diagnosis of Type 1 Diabetes (T1D) and Coeliac Disease (CD).

Method: A systematic search of four databases was conducted. Results were screened and seven papers were included in the final review.

Results: Findings from seven papers revealed equivocal results. Findings from four studies examining health-related quality of life (HRQoL) were contradictory and dependent upon the measures used to assess HRQoL. Two further studies identified an increased risk of depression and reduced social functioning in T1D and CD. Several methodological weaknesses were identified therefore findings should be interpreted with caution.

Discussion: The current review highlights a paucity of rigorous research in this area. A greater understanding of the psychological impact of a dual diagnosis of T1D and CD is needed.

Part Two: Research Report

Introduction: T1D and CD are both autoimmune conditions. Young people with T1D are at increased risk of developing CD. Little is known about young people’s experiences of managing a dual diagnosis of T1D and CD. The aim of the current study was to develop a model of how young people manage a dual diagnosis of T1D and CD.

Method: Eight young people aged 11-16 years (six female, two male) were interviewed about their experiences of managing a dual diagnosis of T1D and CD. Interviews were transcribed and analysed using grounded theory.

Results: A model of young people’s management of a dual diagnosis of T1D and CD was constructed with a central process of ‘feeling forced to stand out, and trying to fit in’. Three main categories of ‘people who help me’, ‘things I do’, and ‘just being myself’ comprised this process and were important factors in managing T1D and CD.

Discussion: Findings highlighted the social impact of a dual diagnosis of T1D and CD. Clinical implications and further research are discussed.

Part Three: Critical Appraisal

The critical appraisal presents a reflective account of the research process.
Acknowledgments

I would like to thank the young people who agreed to take part in this study, without their contribution this research project would not have been possible.

I want to thank Dr Camilla Watters and Dr Amandeep Samrai for helping me develop and shape this study and for their valued ideas and feedback along the way. I would also like extend my thanks to Dr James Greening and Dr Gomathi Margabanthu.

I would like to thank my academic supervisor Mary O’Reilly for the patience, guidance, and encouragement she has shown me throughout the research process.

I want to thank my sister Charlotte for offering me inspiration and new perspectives when I needed it most.

I would like to extend a special thank you to my husband Gareth for his love and support, grounding and containment, and patience throughout this process; I really couldn’t have done this without him.
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Part One

Literature Review

A systematic review of literature examining the psychological impact of a dual diagnosis of Type 1 Diabetes and Coeliac Disease

By

Nathalie Gray
1. Abstract

1.1 Introduction
Type 1 Diabetes (T1D) and Coeliac Disease (CD) are both autoimmune conditions. The prevalence of CD in T1D is approximately 20 times higher than in the general population and reported to be between 3.3% and 11.1%. Research has suggested evidence of psychological stressors in response to the management of chronic health conditions such as T1D or CD. The current review aimed to systematically examine evidence to establish what is currently known about the psychological and social impact of a dual diagnosis of T1D and CD.

1.2 Method
A systematic search of medical and nursing databases of Medline, EMBASE, CINAHL and psychological journals indexed by PsychInfo was conducted to identify literature on the psychosocial impact of T1D and CD on 11th December 2015 and again in April 2016. Searches returned 375 results and seven papers were included in the final review.

1.3 Results
Seven papers examined psychosocial constructs of psychological morbidity, health-related quality of life (HRQoL), and family responses to a gluten-free diet. Findings revealed equivocal results. Four studies examining HRQoL were contradictory and dependent upon the measures used to assess HRQoL. Two studies identified an impact on psychological and social functioning such as an increased risk of depression, reduced social functioning, and gender differences in adults self-reported HRQoL. However these findings should be interpreted with caution. Several methodological weaknesses were identified including small sample sizes, biased recruitment procedures, limited use of reliable and valid measures and limited control of potential confounding factors.

1.4 Conclusion
Methodological issues were numerous. Therefore the current review cannot offer any firm conclusions regarding the psychosocial impact of a dual diagnosis of T1D and CD. Findings highlighted a paucity of psychological research in this area and a greater understanding of the psychological impact of a dual diagnosis of T1D and CD is needed.
2. Introduction

2.1 Clinical Context

Diabetes Mellitus is a chronic autoimmune condition (Levy, 2011). Autoimmune damage to the pancreas results in difficulties producing insulin. Insulin is a hormone which helps glucose, sourced from carbohydrates in foods, be metabolized in the body for energy (Levy, 2011). Type 1 Diabetes (T1D) develops if the pancreas cannot produce any insulin. If the amount of glucose in the blood becomes too high, it can cause serious damage to the body's organs resulting in long-term complications (Levy, 2011). If not detected and managed early, these complications can result in blindness, kidney failure and foot ulceration leading to amputation, as well as premature heart disease, stroke and death (NICE, 2015a). Recent figures reported by Diabetes UK estimate the global diabetes prevalence for adults (20-70 years) for 2015 was 415 million and it is estimated that 10% of those with diabetes have T1D (Diabetes UK, 2015). T1D is treated by insulin therapy, taking insulin via injections or an insulin pump and requires regular monitoring of blood glucose levels (NICE, 2015a).

T1D and Coeliac Disease (CD) are both autoimmune diseases. A relationship between T1D and CD has been documented since the late 1960s (Goh & Banerjee, 2007). The prevalence of CD in T1D has been reported to be 3.3–11.1% (Barera et al., 2002; Uibo et al., 2010; Bhadada et al., 2011). Some of the variation in prevalence rates can be attributed to the different diagnostic criteria used in the studies. CD is defined as a state of heightened immunological response to ingested gluten in genetically susceptible people (NICE, 2015c). Gluten is a protein that is present in wheat, barley and rye and ingestion of gluten in people with CD can lead to significant damage to the mucosal lining of the intestine (Griffiths, 2008). Symptoms of CD include diarrhoea, growth delay in children, nausea and vomiting, fatigue, abdominal pain, weight loss, and anaemia (Griffiths, 2008; NICE, 2015c). There is growing evidence to suggest that people with T1D are at increased risk of CD (Goh & Banerjee, 2007). Further, CD can often be asymptomatic in T1D which indicates a need for routine screening for CD in T1D to manage risks associated with both conditions (Goh & Banerjee, 2007; Mimnagh & Thornton, 2006). There are no medical interventions for the treatment for CD. People with CD are required to follow a life-long gluten free diet (GFD) in order to manage the symptoms and reduce risks associated with CD (2015c).
The treatment for T1D is complex and demanding involving a complicated routine of regular monitoring of blood glucose levels, monitoring nutritional intake, taking exercise, and administering insulin injections (Levy, 2011). These tasks are fundamental in maintaining healthy blood glucose levels to prevent short- and long-term complications (NICE, 2015a; 2015b). It is also important for people with T1D to eat a healthy balanced diet, take regular exercise (to maintain balanced blood glucose levels) and to attend clinics to have regular blood tests to monitor metabolic control of blood glucose levels (NICE, 2015a). People living with both T1D and CD face additional challenges. Alongside the need for close monitoring of blood sugars and nutritional intake, eating a GFD is fundamental to ensuring good physical health and wellbeing (Griffiths, 2008).

2.2 Psychological factors in T1D or CD

Research has suggested that people may experience significant psychological stressors in response to the diagnosis of chronic health conditions (Compas, Jaser, Dunn, & Rodriguez, 2012; Liddy, Blazkho, & Mill, 2014). Chronic health diagnoses such as T1D and CD are often experienced as a life-changing event requiring changes in cognitions, emotions and patterns of behaviour in adjusting to and managing the conditions (Martin, Nunez, & Royo, 2012). NICE guidelines for T1D (2015a) identify the need to consider psychological difficulties in optimising insulin therapy and to be alert to the development or presence of clinical or subclinical depression and anxiety in the context of difficulties with self-management. In children it is recommended that timely and ongoing access to mental health professionals is important because they may experience psychological problems (such as anxiety, depression, behavioural problems and family conflict) that can impact on the management of diabetes and wellbeing (NICE, 2015b). Guidance for CD (NICE, 2015c) highlights the risks of anxiety and depression that may impact on adherence to a GFD.

In a sample of 110 adults with T1D, prevalence rates were found to be 60% for anxiety symptoms and 53.6% for depressive symptoms (de Ornelas Maia et al., 2014). Another study reported that a high prevalence of anxiety and depression in adults with T1D was related to lower quality of life (de Ornelas Maia et al., 2013). Psychosocial and behavioural factors such as low social support, low generic quality of life and difficulties
in managing diabetes are associated with high emotional burden in people with T1D (Joensen, Almdal, & Willaing, 2016).

Adults with CD have reported more depressive symptoms than healthy controls (Smith & Gerdes, 2012). Another study reported that anxiety and depression were associated with lower levels of treatment adherence (Addolorato et al., 2004). However GFD adherence of more than five years appeared to be a factor in reduced symptoms of depression over time (van Hees, van der Does & Giltay, 2013). White, Bannerman and Gillet (2016) reported psychological burdens associated with living with CD, including the cost, access and availability of gluten-free (GF) foods, and difficult social dilemmas. Adolescents have reported experiencing stigmatisation and isolation in social situations, particularly at school (White et al., 2016).

Other measures of psychological functioning have included health-related quality of life (HRQoL). HRQoL evaluates perceptions of health in the domains of physical, mental, emotional, and social functioning from both individual and family perspectives. A related concept of HRQoL is well-being, which assesses the positive aspects of a person’s life, such as positive emotions and life satisfaction. HRQoL and well-being are widely selected to measure the impact of chronic illness in the literature.

Studies have reported lower subjective wellbeing (Holmes-Truscott, Browne, Pouwer, Speight, & Cummins, 2016) and lower HRQoL in adults with T1D when compared with healthy controls (Awadalla, Ohaeri, Tawfiq, & Al-Alwadi, 2006). Participants with T1D also report significantly reduced HRQoL associated with anxiety and depression symptoms (de Ornelas Maia et al., 2013). Additional medical problems and being young, unemployed and single were also found to be associated with poor HRQoL, however illness duration was not (Awadalla et al., 2006). Similarly CD is also associated with reduced psychological well-being and HRQoL (Ford, Howard, & Oyebode, 2012). This suggests that difficulties in psychological and social functioning along with having additional medical conditions such as CD may impact on HRQoL.

In a 10 year longitudinal survey of children and adolescents with T1D, psychiatric morbidity was reported to be 47.5% including depressive disorder, conduct disorders and generalised disorders (Kovacs, Obrosky, Goldston, & Drash, 1997). A study investigating psychosocial problems in children with T1D reported increased psychosocial difficulties and lower HRQoL than their healthy peers (Boogerd et al., 2015). Research suggests that
both children and adults with T1D and CD are at greater risk of experiencing psychological distress, developing symptoms of anxiety and depression, and experiencing a reduced HRQoL.

2.3 Existing reviews

DeMelo, McDonald, Saibil, Marcon, and Mahmud (2015) examined the association between CD and T1D and aimed to evaluate physical health risks to inform evidence for the use of screening for CD in T1D. CD prevalence rates were reported to be four to six times greater in adults with T1D compared with the general population. Adults with both CD and T1D were found to be at higher risk for microvascular comorbidities, increased mortality and impaired bone health if CD is left untreated (DeMelo et al., 2015). Further studies designed to assess the impact of treatment with GFD in people with a dual diagnosis of T1D and CD were recommended.

Another review of the association between CD and T1D by Carmarca et al. (2012) reported a prevalence of CD in T1D ranging from 4.4-11.1% versus 0.5% in the general population. They recognised that people with T1D had few or mild symptoms of CD or were completely asymptomatic. The adherence to GFD by children with CD and T1D was reported to be below 50%, lower than the 73% of children with CD only. Lower compliance with the GFD was found to be more frequent in asymptomatic people with CD and problems with GFD adherence were found to occur more frequently during adolescence (Carmarca et al., 2012). Based on their findings, Camarca et al. (2012) made recommendations for psychological support for young people with T1D and CD.

Of the two existing reviews, neither DeMelo et al. (2015) or Carmarca et al. (2012) took a systematic approach to surveying the literature. Further research is needed to determine whether affective disorders and poorer quality of life are a feature of T1D and CD.

2.4 Rationale and current aims of the review

The current review aimed to collate relevant research papers for systematic review, to evaluate their findings, and to establish what is currently known about the psychological
and social impact on people living with a dual diagnosis of T1D and CD. The current review aims to address the following research questions:

1. What is the psychosocial impact of a dual diagnosis of T1D and CD?

2. How are psychosocial factors measured in the literature?

3. What are the methodological issues in existing literature and how do these impact on the quality of available research?
3. Method

3.1 Search terms

Medical and nursing databases of Medline, EMBASE, CINAHL and psychological journals indexed by PsychInfo were searched to identify literature on the psychosocial impact of Type 1 Diabetes and Coeliac Disease on 11th December 2015 and again in April 2016. Search terms were adapted according to the requirements of each database and represented the key concepts of ‘type 1 diabetes’, ‘coeliac’, ‘celiac’, ‘psychological’, ‘psychiatric’, ‘psychosocial’, ‘well-being’ and ‘quality of life’. Scoping searches revealed that quality of life was a key psychological concept in the consideration of physical health conditions therefore this was included as search term. A detailed account of the search strategies used for each database are presented in Appendix B.

3.2 Identification and selection of papers

Initial searches generated a total of 375 references. References were exported to a third party referencing software package Refworks and duplicate papers were removed. Titles and abstracts were scanned and reviewed against pre-defined inclusion and exclusion criteria. Full texts of relevant articles were retrieved, read and again reviewed against the inclusion and exclusion criteria. References in the retrieved articles were also hand-searched for other relevant citations. Manual searches of Google Scholar generated no further articles. Grey literature was not included in the search strategy as the current review was limited to peer-reviewed articles only. Seven papers were included in the final review (see Figure 1).

3.3 Inclusion and exclusion criteria

Studies were included in the review if they involved research that included a sample of participants diagnosed with both T1D and CD and included a measure of psychological or social functioning. Studies that reported solely on prevalence rates and/or screening exercises of T1D or CD were excluded along with conference abstracts, books, review articles, research proposals, clinical case reports, and studies not published in English. Due to the small number of relevant results, searches were not limited by publication
dates. Scoping searches revealed a very small number (N=1) of qualitative papers. Qualitative studies were excluded from the current review as this would have resulted in difficulties synthesising results. Inclusion/exclusion criteria is outlined in Appendix C.

3.4 Data extraction

Relevant information specific to the research question was extracted from the research papers using a data extraction form (see Appendix D) developed for the review. Data elements extracted were: author/year, location of study, setting, aim of study, design, sample, outcome measures, conclusions and limitations. Meta-analysis of the results was neither appropriate nor possible due to the small sample and heterogeneity of articles and their methods. Therefore the results are presented as a narrative summary of the findings. Findings are organised under headings according to the particular psychological dimensions examined by the studies.

3.5 Quality appraisal

All of the included studies were medical and observational in nature therefore the ‘Strengthening the Reporting of Observational Studies in Epidemiology’ (STROBE) checklist (Von Elm et al. 2008; Vandenbroucke et al., 2014) was considered to be an appropriate tool for quality appraisal. The STROBE is comprised of twenty-two items relating to the title, abstract, introduction, methods, results and discussion sections of published papers (See Appendix E). It is designed to evaluate the quality of reporting scientific research. An advantage of using the STROBE was its ability to assess the quality of studies with a range of designs including cohort, case-control, and cross-sectional. The STROBE was used as a framework to independently evaluate the quality of each paper. This information was then used to summarise the main methodological strengths and weaknesses across the studies.
Figure 1. Article selection process

- Initial search results
  N=375

- Titles scanned for relevance and excluded based on inclusion/exclusion criteria
  N=208

- Articles exported to Refworks
  N=167

- Duplicates removed
  N=102

- Abstracts retrieved
  N=65

- Abstracts scanned and articles further excluded
  N=38

- Full texts of articles retrieved
  N=27

- Papers further excluded where both T1D and CD were not evaluated and where a psychological variable was not measured

- Reference lists hand searched

- Final Review
  N=7

- Quality appraisal tool applied

N=7
4. Results

The final review comprised seven papers. Information summarising each study is presented in Table 1.

4.1 Study characteristics

Studies were published between 2002 to 2014 and there was significant variability in study objectives. Five studies used a case control design and were cross-sectional in nature (Bakker et al., 2013; Garud et al., 2009; Leeds, Hopper, Hadjivassiliou, Tesfaye, & Sanders, 2011, 2014; and Sud, Marcon, Assor, Daneman, & Mahmud, 2012). A further two studies were cohort studies (Saadah, Zacharin, O’Callaghan, Oliver, & Catto-Smith, 2004; Saukkonen, Vaisanen, Akerblom, & Savilahti, 2002) examining changes in outcome measures over time. All studies took place in hospital outpatient settings.

Four studies (Bakker et al., 2013; Garud et al., 2009; Leeds et al., 2011, 2014) used adult samples with a mean age of 47.64 years (range: 43.2 – 51.5 years) and three studies (Saadah et al., 2004; Saukkonen et al., 2002; Sud et al., 2012) used child samples with a mean age of 12.12 years (range: 11.4 – 13.55 years). Both males and females appeared to be equally represented in the samples (53.5% female; 46.5% male). Information regarding the socioeconomic status and ethnicity of participants was not reported in any of the studies. One study (Leeds et al., 2014) did not provide complete demographic information for control groups.

4.2. Psychosocial impact of a dual diagnosis of T1D and CD

4.2.1 Psychological morbidity

Only one study explicitly examined psychological morbidity (Garud et al., 2009). The authors reported a higher prevalence of depression in adults with both CD and T1D (37%) compared with those with CD alone (15.9%). Findings suggested that having a diagnosis of both T1D and CD was a significant risk factor for depression in the adult population.
Table 1. Study characteristics

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<th>Methodology and measures</th>
<th>Analysis</th>
<th>Conclusions (relevant to current review) and limitations (both described and identified via quality appraisal)</th>
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| Bakker, Pouter, Tushuizen, Hoogma, Mulder, and Simsek (2013), Netherlands | To investigate health related quality of life in adult participants diagnosed with both T1D and CD and compare this with T1D only and healthy controls. | Group 1 N=57 participants with T1D+CD, 60% female, mean age 49 ± 16 years, mean duration T1D 25 ± 16 years, mean duration CD 9 ± 10 years. Group 2 N=57 participants with T1D only, 46% female, mean age 52 ± 14 years, mean duration T1D 26 ± 15 years. Inclusion Criteria >18 years Diagnosis of T1D Biopsy-proven CD Self-reported compliance with GFD | Case-control design Cross-sectional survey (77% response rate) Health-related quality of life (RAND-36; Dutch translation) Diabetes specific quality of life (DQOL) | Mean differences between groups analysed using the Student t-test. Dichotomous variables analysed using the Chi square or the Fisher Exact test. | Conclusions  
- T1D+CD and T1D only did not differ on the RAND-36.  
- Lower diabetes-specific HRQoL (DQOL) regarding diabetes-specific worries and social worries in T1D+CD compared with T1D only.  
- Additional diagnosis of CD has a negative impact on diabetes-specific HRQoL.  
- Additional diagnosis of CD impairs social aspects of HRQoL in people with T1D. Observed on DQOL but not on the RAND-36.  
- Significantly lower HRQoL in T1D+CD compared with healthy controls.  
- Lower social functioning in T1D+CD compared with healthy controls.  
- Gender differences: Women with T1D+CD reported lower general HRQoL in areas of social functioning, vitality, and mental health than men with T1D+CD.  
Limitations  
- Ethnicity was not reported.  
- Selection bias – participants recruited by their physicians.  
- Control group recruited from two other hospitals; not the same source as the sample. |
| Garud, Leffler, Dennis, Edwards-George, Saryan, and Sheth (2009). | To determine the prevalence of psychiatric and autoimmune disorders in participants with CD in the US | Group 1 N=600 with CD, 75% women, mean age 51.5 years, no information regarding CD duration. Group 2 | Case Control Cross-sectional Diagnosis of psychiatric disorders through record review of symptoms | Statistical analyses; no specific tests specified. Chi square tests to analyse categorical data. | Prevalence of depression  
- Prevalence of depression was similar in CD (17.2%), IBS (18.5%) and primary care controls (16%).  
- CD participants with T1D had a higher depression rate (37.1%) than those without T1D (15.9%).  
- After controlling T1D, the prevalence of depression in CD participants was no longer significantly different in participants with and without autoimmune disorders. |
**USA**

compared with control group.

<table>
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<tr>
<th>Group 3</th>
<th>N=200 with IBS, 75% women, mean age 46.7 years, no CD duration.</th>
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Inclusion Criteria

Biopsy proven CD

reported in past medical history.

- CD + T1D increases the risk of depression.

**Limitations**

- Ascertainment of psychiatric diagnoses was unreliable.
- Causation of depression in CD or CD+T1D could not be determined.
- Ethnicity of participants was not reported.
- Duration of diagnoses was not reported.
- Limited information about the source of the sample.

**UK**

To examine the effect of potential CD on important outcomes in participants with T1D.

<table>
<thead>
<tr>
<th>Group 1</th>
<th>N=22 Participants with T1D and potential CD, gender and ethnicity not specified, mean age 46.9 years, mean T1D duration 24 years.</th>
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<td>N=14 participants with T1D and newly identified CD, gender and ethnicity not specified, mean age 44.2 years, mean T1D duration 22.5 years.</td>
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<tr>
<td>Group 3</td>
<td>N=24 participants with T1D only, gender and ethnicity not specified, mean age 46.6 years, T1D duration 28.5 years.</td>
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<td>Group 4</td>
<td>N=76 total participants in the study.</td>
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Case Control

Cross-sectional

Glycaemic control (HbA1c levels)

Microvascular Complications (Peripheral Nerve Assessment & Retinopathy)

Cholesterol (Lipid levels)

Health Questionnaire Short Form-36 (SF-36)

Differences between groups analysed using Kruskal-Wallis test or one way ANOVA.

Comparison between groups was performed using Mann Whitney U test or Student’s t test.

**Quality of life**

- No significant differences in HRQoL between any groups.

**Limitations**

- Gender and ethnicity are not specified.
- Limited demographic information about group 4.
- Small sample size.
- Measure - generic quality of life measure (not disease-specific).
| --- | --- |
| **Inclusion Criteria** | >16 years  
Diagnosis of T1D  
Biopsy confirmed CD |
| To identify undetected CD in T1D and investigate the effect of GFD on microvascular complications in adults with T1D & CD | N=1000 participants with T1D (95.8% uptake) resulting in a sample N=12 new cases of CD in T1D. |
| **Group 1** | N=12 new cases of undetected CD, gender and ethnicity not specified, mean age 41 years, T1D duration 22.5 years. |
| **Group 2** | N=24 participants with T1D only, gender and ethnicity not specified, mean age 41 years, T1D duration 28.5 years. |
| Control group matched for age, gender, diabetes duration, insulin dose, & weight. | Case-control  
Comparisons made at baseline and 1 year.  
Glycaemic control (HbA1c levels)  
Retinopathy prevalence  
Neuropathy prevalence  
Health Questionnaire Short Form 36 (SF-36 v2) |
| Prevalence of CD between cohorts was performed using Fisher’s exact tests.  
Comparison of clinical parameters using Mann Whitney U test.  
Changes over time within groups was analysed using the Wilcoxon signed rank test. | **Quality of Life**  
- No difference in quality of life in any of the domains (all P>0.1) at baseline.  
- Quality of life scores at 1 year after commencing the GFD were not significantly different compared with baseline (P >0.1). |
| **Limitations** |  
- Measure - generic quality of life measure (not disease-specific).  
- Gender and ethnicity not specified.  
- Small sample size. |
<table>
<thead>
<tr>
<th>Country</th>
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<tr>
<td>Australia</td>
<td>To study the effect of gluten-free diet on growth and diabetic control of children with type 1 diabetes mellitus and coeliac disease.</td>
<td>Group 1: N=21 children, 62% female, ethnicity not specified, mean age 7.5 years, mean age at T1D diagnosis 4 years, mean age at CD diagnosis was 7.5 years. Group 2 (Control): N=2 children with T1D only. Control group matched for age, gender, and diabetes duration.</td>
<td>Diagnosis of T1D, Biopsy confirmed CD</td>
<td>Cohort study; Comparison 1 year before GFD and 1 year after GFD</td>
<td>Dietary awareness / GFD adherence: 80% of the sample had 'good' or 'excellent' adherence, 20% had 'fair' or 'poor' adherence. Paired t-tests were used for comparison between baseline and 12 months. No significant differences between groups in age at diagnosis or duration for either T1D or CD.</td>
<td>Ethnicity not specified. Small sample size. Small control group. Dietary awareness assessment not standardised.</td>
</tr>
<tr>
<td>Finland</td>
<td>To evaluate whether CD and the GFD affects growth, glycaemic control, and general well-being of children and adolescents with T1D.</td>
<td>Sample: N=18 children with T1D and CD, 50% female, ethnicity not specified, mean age 11.4 years, mean age at T1D diagnosis 8 ± 4.5 years, mean age at CD diagnosis 12.9 years. No Control Group</td>
<td>Diagnosis of T1D, Biopsy confirmed CD</td>
<td>Cohort study; Comparison 1 year before CD diagnosis vs. 1 year after CD diagnosis. Clinical data and laboratory results 1 year before CD and 1 year after the diagnosis.</td>
<td>Responses to GFD: 8 out of 12 families had encountered difficulties at the introduction of the diet. These difficulties did not correlate with the objective changes in glycaemic control after the diagnosis of CD. At the time of the questionnaire, a mean of 4.7 y after diagnosis of CD (range 1.7–7.9 years), none of the families had discontinued the diet. One family reported limited use of gluten-containing products. Nine of the 12 families felt it was necessary to continue with the diet, although most of them found this difficult and expensive.</td>
<td>Ethnicity not specified. Small sample size. General wellbeing not operationalised and poorly defined.</td>
</tr>
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</table>
To determine the impact of managing CD+T1D on quality of life in families, with attention to the effect of adherence with a gluten-free diet (GFD) and metabolic control.

| N=28 T1D+CD  (80% uptake) | Case Control  
|---------------------------|----------------------------------
| Group 1                   | Cross-sectional survey           | Pediatric Quality of Life  
|                           |                                   | Inventory Generic Core Scale (v4.0) and  
|                           |                                   | Diabetes Module (v3.0)  
|                           | GFD Adherence assessed by a Dietician  
|                           | through 1 day food records and interview.  
|                           | Adherence was categorised into three  
|                           | groups: ‘strictly adherent’, ‘adherent with minor transgressions’,  
|                           | and ‘non-adherent’.  
| Group 2                   | Differences between  
|                           | groups were analysed using independent  
|                           | samples t-test.  
|                           | Paired samples t-tests  
|                           | were used to analyse  
|                           | agreement between  
|                           | child and parent  
|                           | reports.  

Quality of life
- Additional diagnosis of CD does not impair HRQoL.  
- No significant differences in self-reported quality of life parameters between children in the T1D group and children in the CD+T1D group.  
- Parents of the CD+T1D group reported lower social functioning scores for their children than parents of children with T1D alone.  
- Parents of children with CD+T1D reported significantly lower scores for psychosocial and social functioning and diabetes treatment barriers than their children.  
- Parents of children with T1D reported significantly lower scores for emotional functioning, diabetes treatment barriers, and communication than their children.  
- In the CD + T1D group, no differences in any quality of life domains were observed in regard to age at CD diagnosis or duration of CD.  
- On the basis of age at quality of life assessment, older children (>13 years) reported significantly more worry in regard to their diabetes than younger children.  
- No differences in HRQoL on the basis of adherence with a GFD between the two groups.  

Limitations
- Ethnicity not specified in demographics.  
- Small sample size.  
- Cross-sectional; included varied experiences of CD duration.  
- Repeat serological testing of CD to support adherence assessment not available for all participants.
4.2.2 Health-related Quality of Life

Findings regarding the impact of a dual diagnosis of T1D and CD on HRQoL appeared equivocal and dependent upon the measures used to assess HRQoL. Bakker et al. (2013) reported lower general HRQoL and social functioning in T1D and CD compared with healthy controls indicating an impairment in HRQoL as a consequence of one or both conditions. However Bakker et al. (2013) and Leeds et al. (2011, 2014) reported no significant differences in general HRQoL for adults with T1D and CD when compared with adults with T1D only. This suggests that an additional diagnosis of CD did not lead to any further impact on general HRQoL. This contrasts with findings using a disease-specific measures of HRQoL. Bakker et al. (2013) found lower HRQoL scores in T1D and CD when compared with T1D only using a diabetes-specific HRQoL measure (DQoL; Burroughs, Desikan, Waterman, Gilin, & McGill, 2004). Lower HRQoL scores were found in the domains of diabetes-specific worries and social functioning. This suggested some evidence for increased difficulties associated with diabetes management and social functioning in adults with T1D and CD. Contrasting findings between general and disease-specific HRQoL measures suggested that impairments in HRQoL relevant to T1D and CD may not be fully evaluated on general HRQoL measures.

Gender differences were also reported in adult samples; women with T1D and CD reported significantly lower scores for social functioning, vitality, and mental health on general HRQoL measure, and higher scores for diabetes-specific worries when compared with men with T1D and CD (Bakker et al., 2013).

One study examined HRQoL in children with T1D and CD. Sud et al. (2012) found that an additional diagnosis of CD did not impair HRQoL based on self-reports. However parental reports indicated impaired social functioning in children with T1D and CD compared with parental reports of children with T1D only (Sud et al., 2012). Parents of children with T1D and CD reported lower scores (compared to children’s self-reports) for psychological and social functioning and diabetes treatment barriers. Similarly, parents of children with T1D reported comparatively lower scores for emotional functioning, diabetes treatment barriers, and communication. This may reflect the increased responsibility that parent’s with younger children take for the management of physical health conditions and the availability of gluten-free foods (Sud et al., 2012). Based on parental reports, lower social functioning in children with T1D and CD (Sud et
al., 2012) is consistent with impaired social functioning reported by adults with T1D and CD (Bakker et al., 2013).

4.2.3 Other psychological dimensions

Two studies explored family responses to a GFD. Dietary awareness and adherence was a psychological variable hypothesised to have an impact on diabetes outcomes (Saadah et al., 2004). Self-reported adherence was found to be ‘good’ or ‘excellent’ in 80% of the sample (Saadah et al., 2004). Factors that predicted better adherence were unclear in this study. No significant differences between groups in age at diagnosis or duration for either T1D or CD were reported. Dietary awareness and adherence had no significant impact on diabetic control however findings suggested an impact on growth; the weight-for-age of children who had ‘excellent’ GFD adherence increased over the 12 months following CD diagnosis (Saadah et al., 2004).

Subjective well-being and family responses to a GFD were explored by Saukkonen et al. (2002) using a questionnaire developed for the study. Responses indicated that 66% of families reported difficulties with the introduction of the GFD (Saukkonen et al., 2002) and 75% of families reported perceptions that it was necessary to maintain a GFD. However some commented that the GFD was ‘difficult’ and ‘expensive’ (Saukkonen et al., 2002). Families reported GFD-related problems such as a limited supply of gluten-free products at school and restaurants alongside challenges in making dietary arrangements for trips away from home such as camping and travelling (Saukkonen et al., 2002). Family responses to the GFD did not appear to correlate with any other objective changes found in the study (Saukkonen et al., 2002) suggesting minimal impact of family responses on diabetes-related outcomes.

4.3 Measurement of psychosocial factors in the literature

There was variation in how psychosocial factors were measured in the literature. Psychiatric morbidity was measured by assessing the prevalence of depression in CD and T1D. Quality of life was measured using general HRQoL measures including the SF-36 (Ware & Sherbourne, 1992), RAND-36 (Hays & Morales, 2001) and generic scales of the PedsQL (Varni et al., 2003). Disease-specific measures such as the diabetes module
of the PedsQL (Varni et al., 2003) and the DQOL (Burroughs et al., 2004) were also a feature in some studies (Bakker et al., 2013; Sud et al., 2012). The SF-36 originated from the Medical Outcome Study (MOS) by the RAND Corporation. Following this study a commercial version of SF-36 was released called the RAND-36. Both the SF-36 and RAND-36 include the same set of items developed in the MOS however the scoring of the general health and pain scales is different between versions (Hays, Sherbourne, & Mazel, 1993). HRQoL measures varied between studies. Only two studies used the same HRQoL measure (Leeds et al., 2011, 2014).

Dietary awareness and compliance with a GFD were assessed using non-validated questionnaires developed specifically for the study (Saadah et al, 2004; Sud et al., 2012). Subjective well-being was also assessed using a non-validated questionnaire however the psychological variable of subjective well-being was also poorly defined by Saukkonnen et al. (2012). Psychosocial factors were a primary outcome measure in only two studies (Sud et al., 2012; Bakker et al., 2013). The majority of studies included psychosocial variables as a secondary outcome measure.

4.4 Methodological issues and impact on the quality of research

Quality appraisal of the studies revealed a number of methodological limitations regarding sample size, assessment and timeframes and the methodology and design of the studies.

4.4.1 Sample size

Samples of participants with a dual diagnosis of T1D and CD ranged from 12 (Leeds et al., 2011, 2014) to 600 (Garud et al., 2009) and varied depending on the objectives of the study. The largest sample size examined prevalence rates of psychiatric disorders in CD. Excluding the prevalence study, sample sizes were small. The mean sample size was 24.3 (range: 18-57). Power calculations for sample sizes were only reported for two studies (Garud et al., 2009; Leeds et al., 2011).
4.4.2 Recruitment

Five studies (Garud et al., 2009; Leeds et al., 2011, 2014; Saadah et al., 2004; & Saukkonen et al., 2002) identified all possible cases of CD in the target population of people with T1D and one study (Sud et al., 2012) recruited 80% of possible cases. However, selection bias was evident in one study (Bakker et al., 2013); participants were identified by their physician and self-selected to participate which may have influenced the findings.

4.4.3 Assessment method and timeframes

The quality of the assessment of psychosocial factors was variable. Saadah et al. (2004) and Saukkonen et al. (2002) used questionnaires and measures that were not standardised or validated. A questionnaire assessing dietary awareness and adherence was developed for one study (Saadah et al., 2004). It was unclear how responses were scored and how adherence was categorised. This was not a standardised measure therefore it was difficult to determine its reliability and validity in measuring dietary awareness and adherence with a GFD. Another questionnaire was used to measure subjective well-being (Saukkonen et al., 2012) and included questions about intestinal symptoms before and after CD diagnosis and complications with starting the GFD. This questionnaire was poorly described; it was unclear if this questionnaire had been developed for the study and who completed the questionnaire. It was unclear whether the respondents were children with T1D and CD, parents of those children, or representative of the family as a collective. Garud et al. (2009) reviewed medical records for past medical history, concurrent medical problems and medication lists to determine evidence of a psychiatric disorder. This assessment method was also unreliable; a psychiatric diagnosis was not formally assessed. Rather psychiatric disorders were determined from a retrospective review of symptoms documented in the participant’s medical records.

Assessment timeframes were not disclosed within five of the studies (Bakker et al., 2013; Garud et al., 2009; Leeds et al., 2011, 2014; and Sud et al., 2012). Garud et al. (2009) was not clear about whether the timing of the diagnosis of depression was before or after the CD diagnosis and in some cases, depression was reported to have been present before CD. Therefore it is unclear if these incidences of depression were related to CD. Of those studies that did report on assessment timeframes, the timing of administration varied
between studies. Dietary awareness was assessed at a single time point by Saadah et al. (2004). Saukkonen et al. (2002) assessed family responses to the GFD a mean of 4.7 years (range 1.7-7.9 years) after CD diagnosis. It is possible that variations in the duration of CD and experience of the GFD may impact on dietary awareness. However this is difficult to determine with such a small sample size. Of note, family responses and dietary awareness was largely based on self-report which could reflect a responder bias in using this method of assessment.

4.4.4 Confounding factors

Assessment of the role and impact of psychosocial factors may have been confounded by the presence of other autoimmune conditions in addition to T1D and CD. Whilst Leeds et al. (2011) documented the collation of data on medical co-morbidities, this data did not appear to be considered or reported in the final analysis. Leeds et al. (2014) provided information about a range of co-morbidities in the sample however these did not appear to be controlled for in the analysis. Another potential confounding factor was duration of T1D and CD diagnoses. Diagnosis duration was not directly reported by Saadah et al. (2004), Saukkonen et al. (2002) and Sud et al. (2012), however age at diagnosis was provided. It is important to report and distinguish between age at diagnosis and duration of diagnosis to contextualise the sample. Garud et al. (2009) did not report any information regarding diagnosis duration. Varied durations of T1D and CD may have impacted on the reporting of psychosocial difficulties associated with T1D and CD.
5. Discussion

The current review aimed to critically examine published studies that investigated the psychological and social impact of a dual diagnosis of T1D and CD. Previous reviews have limited their investigations to the impact an additional diagnosis of CD in T1D might have on physical health complications and adherence with a GFD.

5.1 Summary of findings

The studies in the current review suggested some evidence that a dual diagnosis of T1D and CD has an impact on psychological and social functioning including an increased risk of depression, reduced social functioning, and gender differences in adults self-reported HRQoL. However, these findings should be interpreted with caution due to a number of limitations identified within the studies. The current review was comprised of a multinational sample of papers therefore some differences in the findings may be due to different cultural factors and differences in how healthcare systems provide care for T1D and CD.

Information on the psychological morbidity of T1D and CD was limited to one study (Garud et al., 2009). Whilst results indicated an increase in the risk of depression in adults with T1D and CD (Garud et al., 2009), this study had several methodological limitations and was only able to report an association. Causal links to depression were therefore could not be made.

Findings from four studies (Bakker et al., 2013; Leeds et al., 2011, 2014; Sud et al., 2012) examining the impact on HRQoL were also contradictory and dependent upon the measures used to assess HRQoL. Interestingly, one study (Sud et al., 2012) highlighted differences in child and parent responses; children with both T1D and CD appeared to perceive less impact on HRQoL than their parents. Therefore an additional diagnosis of CD appeared to be associated with reduced social functioning as reported by parents only.

Two studies (Saadah et al., 2004; Saukkonen et al., 2002) examined family responses to the GFD including dietary awareness in relation to the GFD. Findings regarding the impact of family responses and dietary awareness on diabetes-related outcomes of adherence to a GFD were inconclusive due to small sample sizes and potential biases in the responses. Furthermore, Garud et al. (2009), Saadah et al. (2004), and Saukkonen et
al. (2002) all used questionnaires and measures that were not standardised or validated which further compromised the reliability and validity of the findings.

The current review revealed a very limited number of both quantitative and qualitative studies examining the psychosocial impact of T1D and CD. This appears to reflect a paucity of psychological research in this area. T1D and CD are both physical health conditions therefore biological factors, genetic factors, physical health and treatment outcomes appear to have been prioritised for research and publication. Psychological variables were not always a primary outcome measure in medically-based studies. The prevalence of CD in T1D is between 3.3% (Uibo et al., 2010) and 11.1% (Bhadada et al., 2011). This reflects a relatively small population which may result in recruitment difficulties within research studies. The first study was published in 2002 suggesting that this still is relatively new area for research.

Of the studies reviewed, there were common methodological weaknesses including small sample sizes, potential bias in recruiting participants, limited use of reliable and valid methods to measure psychological variables, and poor control of potential confounding factors such as time of assessment, diagnosis duration, and the presence of other autoimmune conditions. This suggests a limited evidence base and great heterogeneity in how studies have addressed psychological issues. The use of varied and often poorly defined psychological constructs, and studies designed without a clear theoretical basis make it difficult to draw any meaningful comparisons between studies. Methodological issues were numerous therefore the current review can offer no firm conclusions regarding the psychosocial impact of T1D and CD.

5.2 Limitations of the current review

This review focussed specifically on the psychological impact of a dual diagnosis of T1D and CD. A systematic approach was taken to examining the literature, applying rigorous inclusion/exclusion criteria and quality appraisal to fully evaluate the evidence base. However there may be limitations to this approach. Search terms and pre-defined inclusion and exclusion criteria may not have captured the full range of relevant articles. Results may have also been biased by limiting the selection of papers written in English.
5.3 Clinical Implications

The review highlighted a number of methodological weaknesses, equivocal findings, and difficulties in synthesising information, therefore only tentative clinical implications can be offered.

It is unclear if people with a dual diagnosis of T1D and CD are at increased risk of mental health problems. However previous studies have reported that people with a single diagnosis of T1D (de Ornelas Maia et al., 2014) or CD (van Hees et al., 2013; Smith & Gerdes, 2012) are at risk of depression. It is therefore important to continue to screen and assess for potential difficulties in psychological functioning in people presenting with difficulties in managing both T1D (NICE, 2015a, 2015b) and CD (NICE, 2015c).

It has been suggested that a dual diagnosis of T1D and CD may have a detrimental effect on social functioning in both young people (Sud et al., 2012) and adults (Bakker et al., 2013) therefore it is important to consider levels of social competence in people presenting with difficulties in managing T1D (Jaser & White, 2011) and CD (Addolorato et al., 2008). Differing views have been reported between children and their parents (Sud et al., 2012) therefore it is important to continue to consider issues from a range of perspectives, especially in young people (Martin, Nunez, & Royo, 2012). It also appears important to consider the barriers that people might face in introducing and maintaining a GFD (Rajpoot et al., 2015) in the context of managing T1D. This may be an important factor in future compliance with a GFD for people with T1D.

5.4 Future Research

Existing research has begun to examine the psychological aspects of managing a dual diagnosis of T1D and CD. However the current review has found very limited research investigating the psychological impact of managing both T1D and CD. Future research should continue to examine the psychological and social impact of the additional diagnosis of CD in T1D. More rigorous studies are needed to develop a greater understanding of the psychosocial impact of a dual diagnosis of T1D and CD. Qualitative studies are also needed to explore in depth, both the experience and impact of managing T1D and CD. Further research would be helpful in informing assessment, formulation,
and intervention work with people living with T1D and CD who may be at risk of developing psychological distress in response to managing both conditions.

5.5 Conclusions

This was the first review to have focussed specifically on the psychosocial impact of a dual diagnosis of T1D and CD. Findings were equivocal therefore only tentative conclusions can be drawn. The current reviews highlights a paucity of psychological research in this area and a greater understanding of the psychological impact of a dual diagnosis of T1D and CD is needed.
6. References

* denotes papers included in the review


Part Two

Research Report

Exploring young people’s management of a dual diagnosis of

Type 1 Diabetes and Coeliac Disease

By

Nathalie Gray
Exploring young people’s management of a dual diagnosis of

Type 1 Diabetes and Coeliac Disease

1. Abstract

1.1 Background

T1D and Coeliac Disease (CD) are both autoimmune conditions. Young people with T1D are at increased risk of developing CD (Goh & Banerjee, 2007). Existing research has mainly investigated young people’s experiences of T1D or CD. It is important to understand young people’s experiences of managing a dual diagnosis of T1D and CD to inform interventions to support young people and their families. The aim of the study was to develop a model of how young people manage a dual diagnosis of T1D and CD.

1.2 Method

Eight young people aged 11-16 years (six female, two male) were interviewed about their experiences of managing a dual diagnosis of T1D and CD. Interviews were transcribed and data was analysed using constructionist grounded theory. Data collection and analysis was completed concurrently. Interviews were guided by the ongoing grounded theory analysis.

1.3 Results

A model of young people’s management of a dual diagnosis of T1D and CD was constructed with a central process of ‘feeling forced to stand out, and trying to fit in’. Three main categories of ‘people who help me’, ‘things I do’, and ‘just being myself’ comprised this process and were important factors in managing T1D and CD.

1.4 Discussion

This is the first known model to capture how young people manage a dual diagnosis of T1D and CD. Findings highlighted the social impact of T1D and CD. Clinical implications include tailoring interventions to take account of the young person’s stage of development and the social consequences of living with a dual diagnosis of T1D and CD. Further research to extend the model and explore the potential applicability to other areas of chronic health is recommended.
2. Introduction

2.1 What is Type 1 Diabetes?

Type 1 Diabetes (T1D) is a chronic condition resulting from autoimmune destruction of insulin-producing beta cells in the pancreas (Levy, 2011). The pancreas produces a hormone called insulin which facilitates the passage of glucose into the body’s muscle and fat cells to be used for energy. In T1D, damage to the pancreas results in difficulties producing insulin. Glucose cannot enter the cells without insulin, therefore glucose levels begin to rise in the blood (Hanas, 2003). If blood glucose levels become too high, it can cause serious damage to the body's organs (Hanas, 2003). Potential long-term complications include blindness, kidney failure, foot ulceration leading to amputation, premature heart disease, stroke and death (NICE, 2015a). T1D is treated by insulin therapy, administering insulin via injections or insulin pump therapy and requires regular monitoring of blood glucose levels (NICE, 2015a; NICE 2015b). It is important for people with T1D to eat a healthy balanced diet and take regular exercise to maintain balanced blood glucose levels. People with T1D attend diabetes clinics and have regular blood tests to monitor control of blood glucose levels (NICE, 2015a; NICE 2015b).

T1D is becoming increasingly prevalent in children and young people. In 2015 there were 31,500 young people with diabetes under 19 years in the UK; approximately 95.1% had T1D (Diabetes UK, 2015). The peak incidence for T1D is reported to be during adolescence, between 10 and 15 years (Diabetes UK, 2015; Levy, 2011). Adolescence is considered to be a critical period in human development characterised by significant physical, cognitive, emotional and behavioural changes (Coleman & Hendry, 1999). During adolescence there is a focus on developing the ‘self’ outside of family relationships, achieving inclusion in a peer group and adjusting to social norms as they progress into adulthood (Coleman & Hendry, 1999). As a result of these changes, adolescence can be a difficult time for many young people. Research has shown that these difficulties can be further complicated and compounded by other factors such the diagnosis of a chronic illness (Hagell et al. 2013).

Evidence suggests that young people are finding it increasingly difficult to manage their T1D. In 2013/2014 less than 18.4% of young people achieved the recommended blood glucose levels of 7.5% (Royal College of Paediatrics and Child Health, 2015). Young people are likely to experience challenges associated with the management and treatment
of T1D such as attending regular health appointments, restrictions on their activities, and a dependence on parents, siblings, and peers for support (Hagell et al. 2013) at a time when gaining independence is a focus.

2.2 Experiences of Type 1 Diabetes

Studies exploring adolescents’ experiences of managing T1D have highlighted challenges associated with feeling ‘normal’ (Marshall et al. 2009), and experiences of T1D attracting unwanted attention in the context of managing a specific self-care routine (Dickinson & O'Reilly, 2004; Huus & Enskar, 2007). Adolescents with T1D have reported experiencing difficulties in managing blood glucose levels, maintaining self-care activities (Freeborn et al. 2013) and managing relationships with parents and peers (Davidson et al. 2004). Adolescents considered that diabetes had to be in balance with their lifestyle (Schur et al. 1999) and expressed a need to be organized and responsible in planning ahead for things to manage their T1D successfully (Carroll & Marrero, 2006; Spencer et al. 2012). Adolescents reported a need to be on time for meals and injections which often impacted on how they spent their day (Huus & Enskar, 2007). Research has also suggested that some adolescents have had positive experiences of living with T1D; they had developed knowledge about their bodies and the importance of healthy food and exercise (Huus & Enskar, 2007). Positive self-care attitudes and feeling responsible for their self-management were found to be associated higher levels of metabolic control (Scholes et al. 2013). Adolescents reported that the more experience they had with self-management tasks, the less stressful they found living with T1D (Carroll & Marrero, 2006). Some adolescents reported experiencing valuable lessons in self-management through their mistakes (Spencer et al. 2012).

2.3 The dual diagnosis of Type 1 Diabetes and Coeliac Disease

T1D and Coeliac Disease (CD) are both autoimmune conditions. CD is an adverse autoimmune reaction in response to gluten ingestion in genetically susceptible people (NICE, 2015c). Gluten is a protein present in wheat, barley and rye. Symptoms of CD include diarrhoea, growth delay in children, nausea and vomiting, fatigue, abdominal pain, weight loss, and anaemia (NICE, 2015c). Children with T1D are at increased risk
of developing CD (Goh & Banerjee, 2007). The prevalence of CD in children and adolescents with T1D has been estimated to be between 1% and 10% (Mimnagh & Thornton, 2006; Goh & Banerjee, 2007; NICE, 2015c). Research has also suggested that T1D and CD are commonly diagnosed around the same age (Simell et al. 2010). CD can often present asymptptomatically highlighting a need for CD screening in young people with T1D (Goh & Banerjee, 2007; Mimnagh & Thornton, 2006). Treatment for CD is strict life-long adherence to gluten free diet (GFD).

Adherence to a GFD has been found to vary in the adolescent population. Mayer et al. (1991) reported that 65% adolescents with CD were compliant with a strict gluten-free diet. Erichiello et al. (2010) found 73.5% of adolescents in their sample adhered to a strict GFD, however 26.5% reported occasional or frequent transgressions. Another study by Wagner et al. (2016) reported that 80.8% of adolescents were adherent with the GFD in their sample.

2.4 Experiences of Coeliac Disease

Qualitative studies exploring young people’s experiences of CD have suggested difficulties in acknowledging and accepting a diagnosis of CD and maintaining adherence to a GFD. Pertinent factors affecting compliance with a GFD are the availability and cost of gluten free foods (MacCulloch & Rashid, 2014). Further, the sensory quality of gluten-free foods has been perceived to be much less satisfactory compared to gluten-containing foods (Olsson et al. 2008; Olsson et al. 2009). Difficulties with adherence may also be associated with CD being undetected in asymptomatic individuals (Rosen et al. 2011). Symptoms after gluten ingestion and knowledge about the consequences and long-term complications of not following a strict GFD were found to increase the likelihood of compliance with GFD (Olsson et al. 2008).

Living with CD and adherence to a GFD are reported to have a significant impact on social functioning in young people. Adolescents reported experiencing stigma associated with following a GFD (Olsson et al. 2008) and that having CD resulted in them being ‘the centre of attention’ (Olsson et al. 2009). In the context of socializing with others and eating away from home, adolescents considered that complying with the GFD had the effect of making an ‘invisible problem’ visible to others (Olsson et al. 2009). This is particularly apparent in situations where adolescents might need to ask about food in
restaurants or canteens and make requests for gluten-free meals. Adolescents also reported negative attitudes and a lack of knowledge about CD in their community including teachers and catering staff (Olsson et al. 2008; Olsson et al. 2009). This often amplified the social consequences of having CD leading to feelings of embarrassment and guilt (Olsson et al. 2009). Adolescents have reported limited confidence in others to prepare gluten-free meals (Olsson et al. 2009) which impacted on their motivation to be spontaneous in their visits to friends’ houses or in attending social events without careful planning (Olsson et al. 2009). However some adolescents reported taking personal control over availability of gluten-free food by preparing gluten-free food at home (Olsson et al. 2008).

Research has suggested that young people with CD experience feeling ‘different’ from others (Olsson et al. 2008, Olsson et al. 2009; Rosen et al. 2011). Adolescents described attempts to ‘fight for normalization’ employing strategies that serve to reduce the impact CD may have on social situations (Rosen et al. 2011). Some adolescents reported responding to both felt and enacted stigma by withdrawing from others, describing their experience as a ‘lonely struggle’ (Rosen et al. 2011). Adolescents also reported difficulties in accessing social support and communicating their needs to others in their social group (Rosen et al. 2011). Some adolescents reported that the social consequences of having to follow a GFD are so aversive that they considered that complying with treatment for CD was ‘not worth the (social) cost’ (Rosen et al. 2011).

2.5 Literature on Type 1 Diabetes and Coeliac Disease

Most of the available research on the dual diagnosis of T1D and CD in young people is quantitative in nature. Quantitative studies have focused on investigating the relationship between the age of onset for each diagnosis (Simell et al. 2010), prevalence rates of CD in T1D (Goh & Banerjee, 2007), quality of life (Sud et al. 2012), and the effects of a gluten-free diet (GFD) on metabolic control in T1D (Levy-Shraga et al. 2012; Sanchez-Albisua et al. 2005; Saukkonen et al. 2002; Taler et al. 2012). Published qualitative research exploring young people’s experiences of managing both T1D and CD is limited. However, two qualitative studies exploring family experiences of T1D and CD suggest emerging research in this area. These will be discussed next.
2.6 Family experiences of Type 1 Diabetes and Coeliac Disease

Erickson et al. (2015) explored parental experiences of raising young people with a dual diagnosis of T1D and CD. Participants were 30 parents interviewed about their experiences and data was subjected thematic analysis. This study highlighted an emphasis on considering the short- and long-term complications of T1D over CD. This included the practical challenges associated with providing healthy meals that were gluten free, high costs of supplies for both T1D and CD, and extra time needed for meal preparation to reduce gluten contamination. Parents expressed concerns about their child’s emotional and mental health in the context of feeling ‘left out’ of activities involving food and being exposed to victimization from peers. Parents reported positive experiences with healthcare providers however reported experiencing negative attitudes and misconceptions from people outside of the family (Erickson et al. 2015).

An unpublished qualitative study was conducted by Love (2014). Participants were four adolescents aged 12-18 years and their parents, interviewed about their experiences of living with T1D and CD. Three of the adolescents were on an insulin pump treatment and one adolescent self-injecting. Interviews were analysed as a dyad using an interpretative phenomenological approach (IPA). Results revealed two super-ordinate themes of ‘perceptual loss and protection’ and ‘duality: together but separate’. Findings suggested that both parents and adolescents experienced a sense of loss in their lives, particularly around the adolescents’ relationship with food and their future health. They also perceived a need for ongoing protection against the consequences of living with T1D and CD. T1D and CD was experienced as ‘constant’ in terms of chronicity however there were differences in how this constant was experienced. CD was seen as a ‘consistent constant’ in that there was little variability in terms of the presentation and management of CD. However T1D was seen as a ‘variable constant’; T1D was experienced as more unpredictable and fluctuations in presentation and management can be considerable. There was a clear focus on the management of T1D compared with the CD; this reflected perceptions of CD as ‘straightforward’ and easier to manage compared with T1D. Consideration was also given to the threats and consequences associated with poor management of T1D that are high risk compared with the consequences of poor adherence to a GFD. The majority of adolescents in this study were receiving insulin pump therapy. Different experiences in self-management may exist between adolescents who administer
insulin via self-injection and insulin pump therapy, therefore the experiences with respect to the method of T1D management requires further exploration.

Existing research has looked at young people’s experiences of managing T1D or CD. However, there is limited research on the experiences of young people managing both conditions. The need to monitor and manage blood glucose levels, carbohydrate intake, and physical activity coupled with recommendations to follow a gluten-free diet may present young people with complex challenges that are not fully understood, highlighting a need for further research in this area.

2.7 Main Research Aims and Question

Little is known about young people’s experiences of managing a dual diagnosis of T1D and CD. The current study aims to address this gap in the literature. It is important to understand young people’s experiences of managing a dual diagnosis of T1D and CD to inform interventions on how to best support young people and their families. The aim of the current study was to develop a model of how young people manage a dual diagnosis of T1D and CD.
3. Method

3.1 Design and rationale for methodology

The aim of the study was to explore young people’s experiences of managing a dual diagnosis of T1D and CD therefore a qualitative approach was employed. Data was collected using semi-structured interviews and analysed using a constructionist grounded theory methodology as described by Charmaz (2006).

Constructionist grounded theory was selected as it was developed to understand how people create and construct social realities (Charmaz, 2006). Alternative qualitative methodologies were considered including interpretative phenomenological analysis (IPA). The aim of IPA is to explore lived experience, developing an understanding of the participants’ experience of an event or object from their perspective (Smith & Osborn, 2008). However grounded theory was considered to have the advantages of a focus on the process of how young people manage both T1D and CD. The aim of grounded theory is to develop a model or theory that is ‘grounded’ in the data; being constructed from the participants’ accounts. Therefore grounded theory was considered to be a suitable method to create a theoretical and conceptual understanding of the social processes involved in managing a dual diagnosis of T1D and CD. Grounded theory is also considered to be a valuable qualitative method of analysis where there is limited knowledge about the area of interest (Corbin & Strauss, 2008).

3.2 Epistemological perspective and researcher position

The researcher was a trainee clinical psychologist in her third year of training and adopted a ‘contextual constructionist’ (Madill et al. 2000) epistemological position (see Appendix F).

3.3 Participants

Participants were eight young people (six female, two male) diagnosed with T1D and CD aged between 11 and 16 years. Participants were recruited from National Health Service (NHS) paediatric diabetes outpatient services and a paediatric psychology service in the East Midlands. Recruitment took place between September 2015 and March 2016. A
second site was added in December 2015 to maximise recruitment potential (see Appendix G for chronology of the research process). This was a paediatric diabetes outpatient service located in an adjacent NHS trust. Demographic information is presented in Table 1. Seven participants described their ethnicity as White British, one participant was Asian British. The age at diagnosis of T1D ranged from 1 to 9 years. Five participants had been receiving insulin pump therapy for a duration ranging from six months to three years. Three participants were injecting insulin. Participant’s self-reported HbA1c levels tested at their last review prior to interview ranged from 53 to 69 mmol/mol. The age at diagnosis for CD ranged from two and a half years to nine years. All participants followed a GFD, and seven participants reported experiencing symptoms after gluten ingestion. All participants self-reported testing negative for CD antibodies at their last review prior to interview, suggesting good compliance with the GFD.

3.4 Procedure

3.4.1 Recruitment and pre-interview contact

Consultant Paediatricians leading the paediatric diabetes teams and Clinical Psychologists in the paediatric psychology team were approached to explore potential participation in the research. Clinical Psychologists, Paediatricians and Diabetes Specialist Nurses provided potential participants with an information pack (see Appendix, H, I, and J) prior to attending their regular clinic appointment. At the end of the individual’s appointment, they were invited to discuss their interest in the project. Interested participants provided their contact details and consented to being contacted either via staff teams or by making direct contact with the researcher.
<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age (years)</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Age at T1D onset (years)</th>
<th>T1D duration (years)</th>
<th>Treatment for T1D</th>
<th>Pump duration (years)</th>
<th>Age at CD onset (years)</th>
<th>CD duration (years)</th>
<th>Treatment with a GFD?</th>
<th>Symptoms after gluten ingestion?</th>
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<td>8</td>
<td>4</td>
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<tr>
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</tr>
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</tr>
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<td>-</td>
<td>2.5</td>
<td>12.5</td>
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<td>No</td>
</tr>
<tr>
<td>Sarah</td>
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<td>9</td>
<td>6</td>
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</tr>
<tr>
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<td>Pump</td>
<td>0.5</td>
<td>9</td>
<td>7</td>
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<td>Yes</td>
</tr>
</tbody>
</table>

1 Pseudonyms used to maintain confidentiality.
2 Gender: F=female, M=male.
3.4.2 Screening for eligibility

Nine potential participants were contacted by the researcher and screened via the telephone to assess eligibility for the study. Participants were screened on the basis of the study’s inclusion/exclusion criteria (see Appendix K). Inclusion criteria included young people up to the age of 18 years, however difficulties recruiting from the young adults diabetes team resulted in the final sample being aged up to 16 years only. Eight participants were found to be eligible for inclusion in the study. One participant was excluded as English was not their first language and they would have required an interpreter to participate in the study\(^3\). Eligible participants were invited to arrange an interview at a convenient date, time and location.

3.4.3 Interviews

All participants were interviewed once; six interviews took place at the participants’ homes, one participant was interviewed at school, and one interview was conducted at an NHS site. All interviews were conducted by the researcher. Interviews were semi-structured using open ended questions allowing participants to give as much information as possible about their experiences. Participants were interviewed alone. Parents and/or carers were located close by, either in another room in the participants home or in a hospital waiting area, in the event that participants needed extra support during the interview.

3.4.4 Topic guide

The researcher developed a topic guide (see Appendix L) and consisted of broad open-ended questions around the topics of interest. The topic guide was piloted with a fellow researcher attending a regular qualitative research group. The initial topic guide was designed as a starting point and evolved simultaneously with data collection. New questions were added and less useful questions were removed as the interviews progressed, consistent with ideas of theoretical sampling described by Charmaz (2006).

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\(^3\) Inclusion criteria should have stated ‘fluent in English’ rather than ‘English as first language.’ Of note, no participants fluent in English were excluded from the study.
3.4.5 Data Interpretation

The average interview duration was 66 minutes (range 61-70 minutes). Four interviews were transcribed by the researcher and four interviews were transcribed professionally (see Appendix M). Interview transcripts were analysed in full. Transcripts were read through by the researcher to develop familiarity with the data. Analysis took the form of reviewing and interpreting data through the process of creating codes, concepts, and categories. The first phase of coding began with initial coding; each line was summarised using line-by-line coding (see Appendix N). Constant comparison analysis was used throughout this process; moving back and forth in making comparisons between the data and codes to ensure consistency in coding the data. This led to the second phase of more selective and conceptual ‘focussed’ coding (Charmaz, 2006) which synthesises and explains larger segments of the data (see Appendix O). Memos included detailed reflections and analytical ideas recorded alongside the analysis (see Appendix P). This process led to the development of subcategories and categories (See Appendix Q). Some categories were merged as they reflected similar properties and processes (see Appendix R). The third phase of theoretical coding was used to review focused codes and conceptualise possible relationships between them. This phase moved the coding process towards a more analytic interpretation of the data and supported the process of theory generation alongside the use of memo writing. The relationships between categories were defined and refined to produce a working model of how young people manage a dual diagnosis of T1D and CD. Finally all data was then reviewed to refine the final model. Theoretical sufficiency is reached when categories are considered to be well described and consistent with the data (Dey, 1999). Data collection was ceased after eight participants, therefore theoretical sufficiency (Dey, 1999) could not be fully achieved for the current study.

3.5 Methods to enhance quality

The researcher employed methods to enhance quality consistent with a contextual constructionist approach (Madill et al. 2000, Willig, 2008). Credibility checks (Elliott et al. 1999) were adopted during the research process; the researcher discussed coding and interpretations of the data at a qualitative research group. Coding and categories were also
discussed with research supervisors to ensure clarity of the relationship between the accounts and interpretations and to ensure that these were ‘grounded’ in the data.

In line with guidelines described by Henwood and Pidgeon (1992) an account of the context and the researcher’s position, along with the processes of data collection and analysis are described to enable readers to assess the ‘fit’ between the findings and the data. To maintain self-reflexivity, the researcher kept a research journal documenting assumptions that may influence the data and reflections throughout the research process. A memo on the researcher’s knowledge and assumptions was completed early in the research process prior to interview to support ‘bracketing’ of information (Birks & Mills, 2015).

3.6 Ethical considerations

The research project was approved by the region’s NHS Research Ethics Committee (Appendix S). Participant information was kept confidential except in circumstances where the participant may have disclosed information that indicated a potential risk to themselves or others. Participants were informed of the limits of confidentiality and the procedures for managing any potential risks at the start of each interview. In the event that any risk issues were raised, the researcher explained that this information would be passed on to supervisors. The team responsible for their care and treatment may have also been contacted to ensure their safety. Informed consent was gained initially over the telephone and confirmed with the participants and their parents at the research interview. At interview, the nature of the study was explained with opportunities for questions. As part of the consent process, parental responsibility was clarified for all participants. Both the parents and the participant were asked to sign a consent form (see Appendix T, U, and V) prior to commencing the research interview. Participants were also informed that they could withdraw at any time.
4. Results

A central process of ‘feeling forced to stand out, and trying to fit in’ was constructed from the data. Three main categories occurred in the context of this central process: ‘people that help me’, ‘things I do’, and ‘just being myself’ (see Table 3). A visual model of the process of managing a dual diagnosis of T1D and CD is presented in Figure 1.

![Diagram showing the central process of feeling forced to stand out, and trying to fit in.]

**Figure 1. Young People’s Management of Type 1 Diabetes and Coeliac Disease**

This model represented a process of how participants managed a dual diagnosis of T1D and CD. The central process represents an overarching dialectic of ‘feeling forced to stand out, and trying to fit in’. The main categories of ‘people who help me’, ‘things I do’, and ‘just being myself’ occurred in the context of this overarching process. The main categories, sub-categories and their focussed codes are presented in Table 3.

The central process is described first, followed by the main categories and their properties, followed by the emerging theory. The name of categories and sub-categories are presented in single quotation marks. Focussed codes are presented in italics. Extracts from transcripts are included to explicate the categories. The source of the extract is referenced by the pseudonym of the participant and the corresponding lines of the transcript. Irrelevant text has been excluded from the extract and denoted as (…).
Table 3. Final categories and focussed codes

<table>
<thead>
<tr>
<th>Category</th>
<th>Sub-categories</th>
<th>Focussed codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>People that help me</td>
<td>Help from my family</td>
<td>• Family responses</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Roles in the family</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Inclusive family practices</td>
</tr>
<tr>
<td></td>
<td>Help from my friends</td>
<td>• Friend’s responses</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Support</td>
</tr>
<tr>
<td></td>
<td>Help from doctors and nurses</td>
<td>• Information and guidance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Communication</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Efficiency</td>
</tr>
<tr>
<td>Things I do</td>
<td>What I do for diabetes and coeliac disease</td>
<td>• Developing knowledge and skills</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Structured routines</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Being prepared</td>
</tr>
<tr>
<td></td>
<td>How I think about diabetes and coeliac disease</td>
<td>• Developing independence</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Changing attitudes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Limiting thoughts and emotions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Focusing on the present</td>
</tr>
<tr>
<td></td>
<td>How I am with other people</td>
<td>• Being discreet</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Disclosing to those that ‘need to know’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Keeping explanations simple</td>
</tr>
<tr>
<td>Just being myself</td>
<td></td>
<td>• Integrating aspects of the self</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Finding a new ‘normal’</td>
</tr>
</tbody>
</table>

4.1 Feeling forced to stand out, and trying to fit in

The central process reflected a process of ‘feeling forced to stand out, and trying to fit in’. The researcher considered that this process reflected the main concern cited by participants. Focussed codes were *feeling forced to stand out* and *trying to fit in*.

Participants described how carrying out self-care tasks for T1D and CD impacted on them socially which resulted in them *feeling forced to stand out* from their peers. Tasks associated with T1D such as checking blood sugars, administering insulin via injections or insulin pump, and monitoring their diet and their activities were often noticed by their friends and peers. Participants also described how following a GFD could elicit different reactions in people and along with a feeling that they are being watched and judged by others.
“Like if I was going on a school trip or something I’d be worried about, like, what I’m going to eat and what people are going to say if I’m eating different things and things like that.” (Hannah, 68-70).

For participants it was important to reduce feelings of difference and gain acceptance within their peer group.

“I don’t really like feeling different very much. Because I want to be like everyone else basically, like my friends and not have to think about diabetes or coeliac.” (Katie, 493-494).

Participants engaged in a number of strategies that served to minimise the social impact of T1D and CD, interpreted as a process of trying to fit in. These strategies are explained further in the categories of ‘developing relationships’, ‘evolving strategies’, and ‘changing self-concept’.

4.2 People that help me

This category comprised three subcategories; ‘help from my family’, ‘help from my friends’ and ‘help from doctors and nurses’. The relationships that were developed with family, friends, and healthcare professionals supported them in their management of a dual diagnosis of T1D and CD.

4.2.1 Help from my family

‘Help from my family’ comprised three focussed codes of family responses, roles in the family, and inclusive family practices. Family responses, roles, and practices appeared to be a significant factor in how participants responded to and managed a dual diagnosis of T1D and CD.

Family responses were initially characterised by fear and concern. Participants described having a very vague recollection of either diagnosis and information was limited to what they were told by their parents. However after diagnosis, families responded by engaging in a process of learning about T1D and CD alongside the participants.

“During that time we sort of educated ourselves about what CD was.” (Sarah, 91-92).
Some families had prior experiences of one or both conditions which facilitated this process.

“At home it’s fine because my mum’s coeliac as well, so most of the food we eat is gluten free anyway.” (Hannah, 100-102).

Some participants also experienced positive family responses to the GFD.

“My dad. He loves it...like we will share...he said that he would rather have gluten free.” (Laura, 1940-1945).

Participants cited support from their immediate family both emotionally and practically. Parents were the main source of support and there were clear roles in the family around how this support was provided. Parents took on roles of facilitating communication with school, healthcare professionals, and their friends’ parents around healthcare needs and planning and organising arrangements to attend appointments for T1D and CD.

“They’ll help me to count carbs. They’ll remind me to get certain things if I’m just sort of hurrying out and I forget and everything…getting my prescriptions…taking me to doctor’s appointments, ringing school to get me out of school for the doctor’s appointments.” (Sarah, 485-488).

Other roles included preparing gluten-free meals and snacks and completing diabetes-related tasks, particularly at times when participants were less able to do this for themselves.

“My mum usually prepares like my food beforehand like in case there isn’t anything” (Maryam, 1138-1139).

Having clear roles in the family appeared to enable participants to develop independence and facilitate mastery over their self-management skills.

“I did everything myself from quite a young, from like the very beginning, which makes me feel like I can do it myself... trying to have good control of my diabetes and what I’m eating myself. So that I’m not sort of feeling like I can’t do anything about it and I’m going to just get ill.” (Sarah, 274-278).

Participants also cited support from people in the wider family including grandparents, aunts, and cousins. However, for some participants the level of understanding and support appeared to reduce in the wider family; some family members had difficulties understanding their needs and preparing appropriate foods at family gatherings.
Participants described how their families engaged in inclusive family practices which reduced a sense of feeling excluded or different. This involved eating together, either eating gluten free meals or eating similar meals with the participant’s meal being a gluten free version.

“I wouldn’t feel like that different because my mum has provided me with so much food that’s like similar and almost the same as people around me.” (Anna, 102-103).

When eating out, inclusive family practices included researching places to eat and phoning ahead to ensure that restaurants could provide for the participants and selecting restaurants that provided gluten free food.

4.2.2 Help from my friends

Relationships with friends was an important source of support in managing T1D and CD. Focussed codes included friends’ responses and support, both of which had a significant impact in how participants managed a dual diagnosis of T1D and CD.

Participants described an acute awareness of their friends’ responses to diabetes-related tasks and their dietary selection. Most participants perceived their friends responses to T1D and CD to be understanding and supportive.

“My friends see me prick my finger or play with my pump and they’re like, yeah, it’s just normal. No-one really says anything. My friends ask me like are your levels okay, I’ll check and it’s just normal.” (Anna, 162-164).

However some participants experienced their friends responses as controlling and intrusive.

“I just find them really controlling...probably cos they care about me and they don’t really want me to get high or low.” (Katie, 328-333).

The level of understanding appeared to increase as friends had more experiences with chronic health conditions.

“My best friends...they know loads...but with my diabetic friends they know loads as well because they have it and they know what it’s like.” (Katie, 650-653).

The nature of participants’ relationships with friends also informed their decisions about who and how much to disclose to others about their conditions.
“Like my friends are really trustworthy, so I know they wouldn’t go and tell people. But...if I’m friends with people that I’m not close with, I reckon they would go and tell people.” (Laura, 442-444).

Participants described various types of support in their friendships. For most participants, friends offered support by asking questions and learning how to support them.

“I know which ones would be better for helping, which wouldn’t. Which would be the ones that aren’t at school. But my friends at my school, there’s two of them and they’re good with it as well...they know what to do if I go high or low.” (Katie, 551-553).

Participants also felt supported when friends ensured gluten-free foods were available when they visited them at their house.

“Some of my friends, like my close, close friends obviously they know and when I go round their house they’ll have all the gluten free stuff and everything.” (Hannah, 218-220).

4.2.3 Help from doctors and nurses

This category represented participants’ experiences of ‘help from doctors and nurses’. Participants considered information and guidance, communication and efficiency were essential in supporting their management of a dual diagnosis of T1D and CD.

Participants valued information and guidance from healthcare professionals on how to develop their self-management skills. This included looking at patterns in blood sugar levels to highlight strategies for better control, updates on the latest technology to support the management of T1D, and information on new gluten-free foods.

“I think definitely and doctors and nurses are really helpful cos they can give you little tips on things that you’ve not really realised...you can become a little more efficient...do things better.” (Sarah, 474-477).

Some participants accessed support from a Clinical Psychologist. Participants cited that psychology sessions provided opportunities to talk about their experiences and develop skills in managing difficult thoughts and emotions associated with T1D and CD. Participants found this helpful as it supported them to have a better understanding of themselves and their conditions and to build on their self-management skills.

“It’s helpful because it just lets me learn new things about it, and it helps...to talk about it which I had trouble with...I had to talk to a psychologist about it.” (Katie, 1131-1132).
Participants varied in their experience of communication with healthcare professionals. Some participants felt that discussions with doctors and nurses were limited to evaluating their management of both T1D and CD and feedback about this.

“I don’t look forward to it. Sometimes I do…look forward to it because I don’t know, you can hear good feedback and stuff and also when you know you’ve done something bad like today, I wasn’t looking forward to it cos of my coeliac, I’ve cheated a bit so that’s why I was just a bit on my guard.” (Maryam, 908-911).

Other participants reported having broader discussions about their personal experiences of living with both conditions including emotions and stressors. This resulted in feeling that they had a more personal relationship with the healthcare professionals supporting them.

“They (doctors and nurses) try really hard to just sort of help me be a bit more relaxed and they’ll just talk to you about what you like to do and how you’re getting on at school and is there anything that’s stressing you out like that. Once they get to know you better they know what you’re going say, which is nice because they become closer I think to you as a person.” (Sarah, 560-565).

The style of communication that healthcare professionals adopted in appointments was also important as it had an influence on participants attitudes towards treatment.

“I’m trying to like question how am I going to be…are they (doctors) going to treat me with like ease, or are they going to like push it all down my throat saying you need to do this, you need to do that. I think I’d probably start neglecting again because I don’t like being told what to do and I’m quite stubborn. (Anna, 960-969).

Participants cited a preference for a communication style that reflected understanding, empathy, and encouragement regarding their self-management.

“I think if they took the approach of understanding that it is hard, cos (my doctor) understands that it is hard and she knows that I will struggle and I will have like breakdowns now and then…it’s easier if they’re there like to help you on the rebound and help you like bring you back up and be like you can do this…I think…if they supported me more than they told me what to do then it would, it would like support me to like look after it and everything.” (Anna, 921-929).

Participants valued efficiency in their contact with healthcare professionals including short waiting times and quick appointments. Participants considered routine appointments that were informative and efficient to be the most helpful.
“He’s a good doctor he explains everything well that’s why I like him…his appointments are quicker and…some doctors make you wait for about one or two hours which is quite annoying.” (Maryam, 1037-1041).

4.3 Things I do

This category reflects the strategies participants engaged in to manage a dual diagnosis of T1D and CD and comprised three sub-categories of ‘what I do for diabetes and coeliac’, ‘how I think about diabetes and coeliac’, and ‘how I am with other people’. Strategies were developed to promote effective management of their conditions to promote good health and limit long term complications. Another important focus of these strategies was related to a need to blend in with adolescent culture and reduce the risk of being perceived as different by their peers.

“I think when you have an illness…you have physical things that you have to do, it can make you feel a bit different but…making sure that you have good control so you don’t have to go out of your way to look different I think is quite important.” (Sarah, 865-868).

Participants experienced managing both T1D and CD as revolving their attention between conditions. There was a strong focus on the management of T1D as blood sugars fluctuated throughout the day. T1D required a structured treatment regimen, and the consequences of not following treatment were perceived to be more immediate and serious for T1D. However when difficulties were encountered with the GFD, particularly when symptoms were experienced following gluten ingestion, participants would shift their attention to CD. Once the symptoms of CD were resolved, attention would return to managing T1D.

“I’d say diabetes probably takes centre stage…it is quite serious if you do it wrong. I think with coeliac disease, if you do it wrong you’re going to be really ill, but you’re not going to end up in hospital. You’re just going to feel ill and then you can go back to it.” (Sarah, 584-586).

4.3.1 What I do for diabetes and coeliac disease

Participants engaged in practical strategies to develop efficient management of T1D and promote better adherence with a GFD. Focussed codes included developing knowledge and skills, structured routines, and being prepared.
Developing knowledge and skills was a strategy that developed soon after diagnosis to manage T1D and CD. Participants varied in the level of knowledge they had about T1D which impacted on the strategies they developed. All participants had an understanding of the impact insulin had on the blood sugar levels.

“Like if it, if my bloods are high then it (insulin) will bring it back down…and if its low, obviously I have to take my insulin after I have food…and that makes it better.” (Laura, 586-595).

However some participants had developed a more in depth knowledge of the biology of their body, the impact of T1D and the action of insulin.

“I think it's because the liver asks the body to deliver more glucose, and you've got too much glucose in the body and the insulin is basically the gateway out of the blood cell…it's like trying to get to a key to unlock a safe to get the goods out. The goods is meant to be like the sugar, the safe is the red blood cell, and the insulin is the key.” (Ben, 923-932).

This knowledge led to a greater repertoire of strategies including when and how to administer insulin. Participants also developed knowledge about CD, symptoms of CD, and the GFD. Of particular interest was the availability of gluten free foods and participants and their families invested time in searching for new gluten-free foods.

“You can find the true gems of gluten free…you have to search hard though.” (Ben, 216-217).

Finding new gluten-free foods introduced variation in the GFD and supported better adherence. It also reduced the risk of feeling bored of gluten-free foods and giving in to the temptation to consume gluten-containing foods.

“I think…it is easier to get the same food, but finding new foods is really, it's a bit of a triumph…it makes it a bit more interesting.” (Sarah, 786-793).

Both T1D and CD require monitoring and adjustment to diet, therefore participants considered that some strategies developed to manage T1D were applicable to CD.

“It’s basically the same thing but it’s just in a more advanced way like...watch what you’re eating but in a gluten-free way.” (Maryam, 1091-1092).

Participants developed strategies depending on the timing of their diagnoses. For participants who were diagnosed at same time, diet-related strategies for managing T1D were considered applicable to the management of CD. For participants who were diagnosed with CD later, existing diet-related strategies for T1D were extended and adapted to support the management of CD.
Some participants described stressors related to self-management of T1D and following a GFD and recognised that stress can have an impact on their blood sugars.

“Never get stressed...this physically makes it worse...you go even higher.” (Ben, 508-510).

Some participants developed knowledge about strategies to manage feeling stressed that would help keep blood sugars under control.

“You can just do exercises and stuff to help...just to calm you down a little bit...like breathing ones.” (Oliver, 529-533).

Participants developed structured routines around T1D. This supported the completion of important tasks and facilitated more stable management of blood sugars. Structured routines around meal times also supported participants to adhere with a GFD.

“My doctor said do like a pattern...like you can have breakfast and then a snack, then lunch and then maybe a snack and then tea. And that works as well.” (Katie, 218-220).

Another important strategy was being prepared. This involved frequent checking of equipment and supplies before leaving the house, preparing their own gluten-free food in advance, and carrying gluten-free food and snacks with them.

“I might want like a brownie from school but I can always bring one from home because my mum does provide me with a lot of foods just to make sure that I don’t feel like I’m different.” (Anna, 99-101).

4.3.2 How I think about diabetes and coeliac disease

Psychological strategies of ‘how I think about diabetes and coeliac disease’ included developing independence, changing attitudes, limiting thoughts and emotions, and maintaining a focus on the present.

Developing independence in managing both T1D and CD was important for participants. Participants developed their independence by taking responsibility for their conditions.

“I do most of my diabetes for myself...I do all of my testing...all of my insulin...all of my carb counting for myself.” (Ben, 468-469).

Developing independence and being seen as an ‘expert’ in T1D and CD facilitated a sense of control, and enabled participants to feel confident in their self-management skills.
“It’s stressful as it is and...having ridiculous things done first...someone prioritising the work more than that (diabetes)...it would just be a lot of hassle. I can handle it for myself” (Ben, 832-837).

Having control over T1D was perceived to promote better self-management and reduce the risk of long term consequences of T1D.

“Bad stuff could happen like if you don’t control yourself.” (Maryam, 857-859).

Participants experienced changing attitudes towards their skills and abilities. As strategies developed participants began to have more positive experiences of managing their conditions. This impacted positively on their self-confidence and their perceived ability to manage T1D and CD.

“I find it hard sometimes but I can manage with it cos I’ve had it for a long time. There can be tricky situations but you can always get your head round it.” (Oliver, 18-19).

Some participants cited changing attitudes towards gluten-free foods and their availability which supported better adherence with a GFD.

“Because there’s a wider range of gluten free food, it’s not really affecting me as much as it did...my mum just said you’ve got it for life now, you better get used to it. So I altered my mindset” (Anna, 751-755).

Other participants had mixed views about gluten-free food. Negative perceptions were related to unpleasant tastes and textures of gluten-free food and a limited variety of gluten-free options. Participants citing these attitudes reported more instances of non-adherence with a GFD.

“I prefer the foods for when I don’t have it, than the foods like what haven’t got gluten in it. I just don’t like it.” (Laura, 492-493).

Some strategies were developed in response to the difficult thoughts and feelings associated with T1D and CD, strategies that limit thoughts and emotions.

“I don’t think about it to be honest. I don’t talk about it that much...I just sort try and do things, not quickly, but I will not dwell on being. I won’t make too much time out of it.” (Sarah, 260-264).

When participants felt tempted by gluten-containing foods, they responded by walking away and avoiding thinking about tempting foods.

“I just really want to have it but I normally just walk off...I have to go, because I don’t want to tempt myself anymore.” (Katie, 298-299).
Participants found that eating a gluten-free alternative was also helpful as it served as a distraction from thoughts of temptation.

“If you find something (gluten free) as well, then you kind of just forget about the things that you were missing out on.” (Oliver, 434-437).

Participants demonstrated some awareness of the long-term complications of both T1D and CD, however participants maintained a focus on the present.

“Obviously if I do cheat like they’re (healthcare professionals) just there to tell me don’t do it because obviously you want a bright future. But I’ve not really thought about it though cause I have controlled myself.” (Maryam, 513-515).

4.3.3 How I am with other people

Social strategies of ‘how I am with other people’ were used to facilitate discreet management of T1D and CD to minimise the social impact of both conditions. Focussed codes included being discreet, keeping explanations simple, and disclosing to those that need to know.

Participants prioritised being discreet in their management of T1D and CD. This involved deciding the timing of diabetes tasks when there were fewer people, in locations where people were less likely to notice, and completing tasks in a way that minimised potential attention from others.

“I kind of do it when...because it’s quite busy at lunch time, I kind of do it when it’s sort of settled down a bit and everyone’s in their own conversations so nobody really looks.” (Hannah, 15, 295-297).

Participants also considered that being on insulin pump therapy facilitated discretion at school.

“At school I used to have to go to the medical room and then go to the toilets and inject myself in the toilets...whereas I just do it (use the pump)at the table and stuff, so it’s a lot easier and more convenient.” (Hannah, 15, 285-288).

Participants were often asked questions by people, particularly their friends and peers. This was experienced as exposing and participants expected people to have difficulty understanding their conditions.
“My friend asks why are you not eating this or that I feel quite uncomfortable cause its quite hard to explain and they won’t understand what it is.” (Maryam, 220-222).

They responded to questions by keeping explanations simple; limiting the detail of explanations and the time they spent explaining information.

“I explain what it is and that, in minor detail cause…I don't want to hang around all day.” (Ben, 617-618).

However for some participant’s the experience of explaining to others changed over time. As participants’ knowledge and experience developed, their confidence increased and they felt more able to explain their conditions to others.

“If they don’t understand it…I’m used to lots of other people not understanding it, so…you might have to repeat it sometimes, but most people do understand it in the end.” (Oliver, 472-474).

To maintain discretion about their conditions, participants were also selective in their disclosure; only disclosing to people that ‘need to know’. Decisions about disclosure were based on the nature of their relationships and interactions with people.

“Well, I just tell people...that I eat with...at lunch the people I sit with they all know, people whose houses I go round, they know. And that’s about it really...I just have my friend group and that’s really who I interact with. So there’s nobody else who needs to know, if that makes sense.” (Hannah, 15 241-245).

Practical, psychological, and social strategies evolved over time through trial and error. As participants gained knowledge and experience, they were able to use this information to refine their strategies, improve efficiency at self-management of T1D and CD, and reduce the social impact of both conditions.

4.4 Just being myself

This category represented changes in participants’ self-concept and perceptions of themselves in relation to their peers. Participants described a move towards ‘just being myself’. Focussed codes included integrating aspects of the self and finding a new normal.

A dual diagnosis of T1D and CD introduced additional aspects to their ‘core self’ that required extra care and attention: the ‘diabetic self’ and the ‘coeliac self’. The ‘diabetes
self” was concerned with monitoring blood sugars, monitoring symptoms, diet and exercise, and administering insulin either via injections or insulin pump. The ‘coeliac self’ was concerned with the need to adhere to GFD and potential symptoms associated with gluten ingestion. The ‘core self” was concerned with other aspects of adolescent life outside of T1D and CD such as schoolwork, relationships, and hobbies. As participants developed with their conditions, participants became engaged in a process of integrating aspects of the self.

Participants experienced aspects of the ‘diabetic self” as intrusive directing them away from desirable activities.

“Sometimes I’ll come off the computer just to test it if I’m not feeling right. Sometimes I’ll get out of bed if I’m not feeling alright. And in general, it doesn’t affect much but on the occasion when it does have an impact it can be minor or it can be quite major.” (Ben, 579-581).

Participants experienced the ‘coeliac self” as exposing; following a GFD highlighted differences between themselves and their peers.

“It’s horrible…in McDonalds I have to have it (burger) without the bun, and I feel like people are looking at it like ‘oh why has she got that?’ and I just feel like it’s embarrassing in a way.” Laura (554-556).

Both the ‘diabetic self” and ‘coeliac self” were experienced as competing with activities of the ‘core self”.

“It just gets in the way of like social stuff I guess…like talking to friends…relaxing at home. If you’re just constantly doing your diabetes, that’s when it can get frustrating” (Oliver, 522-526).

Some participants used the concept of time to reflect how they managed competing aspects of themselves. Participants described challenges in balancing time spent on the ‘diabetes self” and ‘coeliac self” to allow for activities of the ‘core self” such as schoolwork, socialising with friends, time with family, and pursuing their hobbies.

“With school and homework interfering with diabetes when I get home as well for like dinner time, that can have an impact…well it can like get in the way, it’s not just homework but like other stuff going on. It can be hard to do at the same time as doing diabetes.” (Oliver, 154-158).

Different aspects of the self were prioritised at different times depending the status of blood sugar levels and health, the environment, social context, and the activities participants were engaged in.
“It might delay on something that I need to do...if I’m about to go into sport then it can effect that...so that’s why I’ve just got to manage time so that diabetes doesn’t get in the way of everything else throughout your day.” (Oliver, 320-322).

It was also recognised that the ‘diabetic self’ and the ‘coeliac self’ could have a positive impact on the ‘core self’.

“It does make me different but it’s not the bad kind of different...it makes me unique because I’m able to stand there and say yeah I’m diabetic, I’m coeliac and then give information on it.” (Anna, 964-966).

Participants were engaged in a process of integrating aspects of the self in relation to T1D and CD. Evolving practical, psychological, and social strategies served to minimise aspects of the ‘diabetes self’ and ‘coeliac self’ which enabled them to maximise aspects of the ‘core self’. Some participants appeared to more advanced in the process of integrating aspects of the self. They considered T1D and CD to be an integral part of them, however it did not ‘define’ them as a person.

“I think it’s really important not to let it define you...I think it’s really important not to be that person with diabetes, just be yourself.” (Sarah, 815-817).

Participants also described normalising their experience of T1D and CD; finding a new normal. Participants noticed differences between themselves and their peers in terms of the activities they had to prioritise for T1D and CD. As participants and their families developed knowledge and experience in managing T1D and CD, they adjusted their perceptions of what they considered normal behaviour; they began to perceive the tasks associated with managing both conditions as ‘normal’ for them.

“You’ve got to go to certain places like you have to go regularly to the hospital for check-ups and things that...normal people wouldn’t have to do. But, when you don’t think about it too much as something that is sort of defining you, you can get past it and you don’t really view it as a limitation, you just view it as sort of what’s going to happen because you can’t stop it happening so you just roll with it and see what happens.” (Sarah, 397-405).

Participants also noted differences in who they socialised with and how they spent their leisure time.

“Like I say usually I don’t mind because I just go (to eat) with my friends or my family who know that I’m going to have something different.” (Hannah, 182-184).
When the GFD was introduced, initial reactions were around feeling ‘cut off’ or ‘giving up’ certain foods. However as participants developed knowledge about CD and the GFD, their relationship with gluten-free food seemed to change. For some participants gluten-free foods were seen as ‘special’ and specific to their needs.

“Gluten-free food is rather special I have found.” (Ben, 727).

For other participants cravings for gluten-containing foods reduced over time as they developed their experiences of following the GFD.

“At the start it was a lot harder than it is now, because I’ve sort of like forgotten some of the things I used to eat, so like you know when you like crave something, I don’t get that anymore because I’ve not had it in a while.” (Hannah, 88-90).

Positive family responses to the GFD also influenced this process. Over time gluten-free foods were seen as a ‘normal’ part of their diet.

“It feels normal cos my mum she makes most things gluten free, so it just feels...like I’m eating normally.” (Katie, 243-244).

4.5 Emerging theory of young people’s management of T1D and CD

Based on the current model, an emerging theory of successful management of a dual diagnosis of T1D and CD is offered. Young people may experience both T1D and CD as exposing which presents them with a social challenge. Early relationships with family, friends, and healthcare professionals may influence how participants respond to and conceptualise T1D and CD, and themselves in relation to their T1D and CD. Positive family responses, clear roles in the family and inclusive family practices foster helpful family relationships. Positive responses and support from friends provide essential networks of peer support. Guidance and open communication with healthcare professionals provide specialist support and advice enabling young people to develop knowledge and understanding about T1D and CD. Positive relationships with family, friends, and healthcare professionals foster a sense of self-efficacy, independence and mastery over T1D and CD, and promotes positive changes in their self-concept. The self-concept moves towards integration, shifting from a focus on the diabetes and coeliac aspects of the self, to a focus on the self as a whole. Supportive relationships and positive changes in self-concept facilitate the development of helpful and adaptive strategies.
These strategies promote the evolution and refinement of self-management skills to manage T1D and CD. Efficient and effective self-management skills support the young person to ‘fit in’, as much as their strategies will allow, with adolescent culture.
5. Discussion

5.1 Summary of findings

The aim of the study was to develop an understanding of how young people manage a dual diagnosis of T1D and CD. Eight young people were interviewed about their experiences of managing a dual diagnosis of T1D and CD. Interviews were transcribed and data was analysed using grounded theory. A central process of ‘feeling forced to stand out, and trying to fit in’ was constructed from the data, and three categories comprised this process: ‘people who help me’, ‘things I do’, and ‘just being myself’. Findings highlighted the social impact of T1D and CD. Participants managed T1D and CD by developing relationships with family, peers, and professionals for support, developing strategies to manage T1D and CD, and adjusting their self-concept. All of these processes occurred within the wider context of trying to ‘fit in’ with adolescent culture.

5.1.1 Social impact of a dual diagnosis of T1D and CD

Participants were mostly concerned with the social impact of T1D and CD as reflected by the central process of ‘feeling forced to stand, and trying to fit in’. This was consistent with previous studies that highlighted issues around feeling ‘normal’ (Marshall et al. 2009) and perceptions that T1D made adolescents ‘stand out’ from their peers (Dickinson & O’Reilly, 2004; Huus & Enskar, 2007). Stigma associated with the social consequences of following a GFD (Olsson et al. 2008) has also been reported previously. This category was also consistent with parental views; a previous study reported parental concerns about their child’s emotional and mental health in the context of feeling ‘left out’ of activities involving food and being exposed to victimization from peers (Eriksson et al. 2015).

In the current study, it was important for participants to reduce feelings of difference and gain acceptance within their peer group. This is thought to reflect challenges characterised by their current stage of development. According to Erikson’s (1968) psychosocial stage model, young people in early adolescence experience a psychosocial dilemma of group identify vs. alienation (Erikson, 1968). This reflects a need for young people to find acceptance within a peer group to satisfy their need for belonging. This normal stage may be further complicated by the presence of chronic health conditions such as T1D and CD (Hagell et al. 2013).
5.1.2 ‘People that help me’

Relationships with family, friends, and professionals were an important source of support for participants. Family relationships were generally perceived as positive and helpful, however it is possible that other adolescents may experience difficult relationships and conflict in their family relationships. This may result in the development of less helpful and maladaptive strategies for managing a dual diagnosis of T1D and CD (Anderson et al. 2002). Interestingly in the current study both participants and their families appeared to share the same goal of supporting the participants to ‘fit in’, engaged in inclusive family practices that served to minimise feelings of difference.

Relationships with friends also played a significant role in how participants managed a dual diagnosis of T1D and CD outside the home. Dovey-Pearce et al. (2007) found that peer relationships supported adolescents’ adjustment to T1D. In the current study, participants were more likely to access support and disclose information about T1D and CD to friends that were understanding and did not respond adversely to diabetes-related tasks or the GFD. Olsson et al. (2009) reported that adolescents had limited confidence in others to prepare gluten-free meals which limited their confidence in visiting friends’ houses. Participants in the current study reported developing a number of close friendships with people they felt they could depend on to provide gluten-free foods. Therefore visiting friends was not cited as a problem by participants in the current study.

Peer relationships and friendships are considered important in adolescence as they form an important source of social support and context within which to learn about relationships outside of the family (Carr, 2006a). Friendships also fulfil an need for belonging (Erikson, 1968). In the current study, participants reported generally positive experiences with friends, whereas previous studies have found that adolescents with CD reported withdrawing from others, describing their experience as a ‘lonely struggle’ (Rosen et al. 2011). It is possible that adolescents with limited access to social support from friends may present with increased difficulties in adjusting to and managing T1D and CD.

In terms of relationships with healthcare professionals, these enabled participants to develop their knowledge and skills in self-management through specialist information
and support (Hynes et al. 2015). They were generally positive about the support they received from healthcare professionals (Hynes et al. 2015). This was also consistent with parental reports of positive experiences with healthcare providers (Eriksson et al. 2015). Participants valued empathic communication that was focussed on them as a whole person rather than limiting conversations to the diabetes or coeliac aspects of themselves (Hynes et al. 2015). A preference for this style of communication appeared to be linked to the participants own efforts in integrating aspects of the self.

5.1.3 ‘Things I do’

Participants engaged in a number of practical, psychological, and social strategies that served to minimise the social impact of T1D and CD, interpreted as a process of ‘trying to fit in’. Of the difficulties in self-management that were reported, they were mostly associated with the social impact of T1D and CD. Findings appeared to contrast with parental experiences that focussed on the practical challenges of managing a dual diagnosis of T1D and CD (Eriksson et al. 2015). This may because parents take on the role of providing and preparing food as adolescents are not yet able to take responsibility for this.

Clear strategies for managing T1D and CD were described and found to evolve over time through experiential learning. This was consistent with a previous study; adolescents reported experiencing valuable lessons in self-management of T1D through their mistakes (Spencer et al. 2012). Participants’ use of practical strategies were similar to aspects of problem-focussed coping described by Zeider and Endler (1996). Developing knowledge and skills was consistent with accepting responsibility and seeking information; and developing structured routines and being prepared was centred around developing realistic plans (Zeider & Endler, 1996). Being prepared was also associated with increased compliance with the GFD in the current study. Although not a major finding it is important to note that practical aspects of managing T1D was improved using insulin pump therapy (Weissberg-Benchell et al. 2003). The pump also reduced social consequences of T1D; participants found in easier to be discreet when on insulin pump therapy (McMahon et al. 2005). Participants developed social strategies to minimise the social impact of T1D and CD consistent with attempts to ‘fight for normalization’ as
described by Rosen et al. (2011). Psychological strategies were considered to be more focussed on managing the impact of T1D and CD on the participants’ own self-concept. Developing independence improved perceived confidence and self-efficacy in their self-management skills (Heaton et al. 2016). Developing independence has been a feature in previous studies; adolescents with T1D expressed a need to be organized and responsible in planning ahead for things to manage their T1D successfully (Carroll & Marrero, 2006; Spencer et al. 2012). Limiting thoughts and emotions served to temporarily distract them from difficult experiences, similar to avoidance-focussed coping (Zeider & Endler, 1996). This strategy appeared to be temporary and functional for participants in that it supported them to remain compliant with the GFD. However it is suggested that longer-term use of avoidance strategies may result in maladaptive coping in the future (Zeider & Endler, 1996). As participants developed their self-management strategies and independence, they reported changing attitudes towards T1D and CD; developing positive appraisals of their knowledge and skills. Changing attitudes appeared to have an positive impact on the participants’ self-concept. Carroll and Marrero (2006) reported that the more experience adolescents had with self-management tasks, the less stressful they found living with T1D. Participants use of changing attitudes in managing T1D and CD was also consistent with the reframing and cognitive restructuring aspects of emotion-focused coping (Zeider & Endler, 1996).

5.1.4 ‘Just being myself’

Living with diabetes can impact upon personal identity and self-concept (Dovey-Pearce et al. 2007). Participants experienced changes in their self-concept as they developed with both T1D and CD and integrating the ‘diabetes’ and ‘coeliac’ aspects of the self with the ‘core self” was essential. Evolving strategies supported participants to maintain a balance in their lifestyle (Schur et al. 1999) achieved by minimising the ‘diabetes’ and ‘coeliac’ aspects of the self and maximising the core self. Engagement in practical, psychological and social strategies supported the development of self-knowledge, self-evaluation, and self-regulation (Harter, 1999) which facilitated a changing self-concept and contributed to the construction of the self (Harter, 1999).
5.2 Comparison with other models

The current model appears analogous to a previous model of self-management of T1D in adolescents (Chilton & Pires-Yfantouda, 2015). Participants reported similar challenges of managing T1D such as blood glucose monitoring, family relationships, accommodating school, and integrating diabetes around others (Chilton & Pires-Yfantouda, 2015). Similarly successful management was associated with taking ownership, developing independence, prioritising diabetes, exposing diabetes to others, and evolving strategies that resulted in gaining momentum in self-management (Chilton & Pires-Yfantouda, 2015). Whilst the social consequences of T1D was captured within the processes of integrating diabetes around others and exposing diabetes to others (Chilton & Pires-Yfantouda, 2015), the social impact of T1D did not emerge as a main focus in this model; a contrast with the current study.

Another model of T1D in adolescents emphasised a process of ‘normalising’ (Babler & Strickland, 2015) and resonates with the changing self-concept aspect of the current model. Normalising was defined as the ability to integrate T1D into the background of daily life by developing routines to make T1D a ‘part of me’ (Babler & Strickland, 2015). Participants in the current study engaged in a similar process of ‘normalising’ both T1D and CD, developing strategies and routines to minimise T1D and CD, maximising other aspects of their life, and adjusting perceptions of their diet and self-care routines to be ‘normal’ for them. Babler and Strickland’s (2015) model captured the young person’s journey from diagnosis through to normalising their experience of T1D. However a hope for a normal future (Babler & Strickland, 2015) was not a major finding in the current study. Participants offered limited reflections on their future and presented with a strong focus on the present. This may reflect a strategy specific to the current sample or that participants in the current study had not yet experienced this phase of Babler and Strickland’s (2015) model.

A previous psychosocial model of managing CD was specific to an adult population (Rose & Howard, 2013). The central category reflected a changed identity for those living with CD (Rose & Howard, 2013) suggesting that adult experiences are comparable with the changing self-concept reported by participants in the current study.
5.3 Strengths and limitations of the current model

The current model is the first known model to capture how young people manage a dual diagnosis of T1D and CD. It identifies social functioning, relationships, strategies, and self-concept as important factors in the self-management of T1D and CD. A strength of the current model is a focus on the social impact of T1D and CD as social functioning is a particularly important aspect of adolescence (Carr, 2006a; Erikson, 1968).

Previous models of T1D (Babler & Strickland, 2015; Chilton & Pires-Yfantouda, 2015) have presented self-management of T1D as a series of stages or continuum that occurs over time. The current model reflects a more dynamic process that evolves as relationships, knowledge, and skills develop with the young person. The current model suggests that changes in one category will lead to changes in another. Developing supportive relationships will lead to increased knowledge and confidence in developing strategies for self-management, impacting positively on the self-concept. Equally poor relationships may reduce opportunities to develop adaptive strategies and result in a negative self-identity around T1D and CD.

Participants in the current study presented with generally positive self-management skills. A limitation of the current model is that it may not reflect the full range of experiences that young people might have in managing T1D and CD. This may be because participants were less likely to disclose negative experiences during interview. Another potential limitation of the model is that it might not be relevant to young people in earlier or later stages of development. Stressors associated with T1D and CD might be experienced and managed differently by young people at different stages of development. A surprising finding and another potential limitation of the model was the limited focus on the experience of the dual diagnosis. This may be because both T1D and CD are diet-related conditions and strategies for managing T1D were considered relevant and applicable to the management of CD.
5.4 Strengths of the study

Previous studies have focused on developing an understanding of adolescent and family experiences of living with both T1D and CD (Erickson et al. 2015; Love, 2014). The current study used grounded theory which enabled the analysis to go beyond descriptive to develop a model about how young people manage a dual diagnosis of T1D and CD. The use of quality checks and a clear audit trail were also strengths of the study.

5.5 Limitations of the study

5.5.1 Recruitment

Selection bias may have occurred during two different stages of recruitment. Firstly, healthcare professionals were responsible for the identification of potential participants to be approached about the research project. Secondly, there may have been a bias in the participants who selected to engage in the study. It is possible that young people who feel more confident about their self-management skills are more likely to talk about their experiences.

5.5.2 Sample

The majority of participants were White British. Participants from minority ethnic backgrounds were considerably under-represented in this sample. Family culture, ethnic background, and socio-economic status of families might influence how young people respond to, conceptualise, and manage T1D and CD (Edmonds-Myles et al. 2010). The majority of participants were female therefore gender differences in the management of T1D and CD could not be explored in the current study. Family members were not interviewed for the current study. Whilst the study captured young people’s individual experiences, these were not explored in the family context. It is possible that participants may have minimised the role of others, including family, in supporting them to manage both conditions. Therefore a different set of findings may have been concluded when explored in a family context. Participants in the current study self-reported relatively good blood glucose control and maintaining a satisfactory level of adherence to the GFD. Self-
reports may have been biased and glycaemic control can fluctuate considerably in adolescence (Chowdhury, 2015).

5.5.3 Design

Grounded theory was considered to be the most appropriate method in meeting the aims of the study. Data was generated using semi-structured interviews. Theoretical sampling was achieved through modification of the topic guide to guide data generation and analysis to support the development of the current model. Initial questions were guided by the aims of the study and the topics of interest. In later interviews, questions were focussed around the categories being developed during analysis. Grounded theory also advocates the use of negative cases in analysis. This allows the researcher to identify cases or incidents that do not fit the data, adding complexity to the model (Charmaz, 2006, Corbin & Strauss, 2008). Theoretical sampling of participants including negative case analysis was limited in the current study due to a limited pool of potential participants and the practical difficulties of identifying young people with varied experiences of managing a dual diagnosis of T1D and CD.

5.6 Clinical implications

5.6.1 Implications for healthcare professionals

Based on the findings of the current study, it is important for healthcare professionals to be aware of the impact of different styles of communication on engagement and compliance. Authoritative styles of communication may have a negative impact on compliance (Hynes et al. 2015). Empathic and collaborative styles of communication are considered to foster more positive working relationships and promote better treatment adherence (Hynes et al. 2015). In addition to discussions about T1D and CD during appointments, it is important to structure conversations around wider aspects of the young person’s life to support integration of the self (Hynes et al. 2015). Discussions regarding stressors and coping with the social challenges in adolescent life may be helpful in identifying potential barriers and difficulties in managing a dual diagnosis of T1D and CD (Christie, 2012). Young people appear to have a preference for efficient and timely
appointments. It is important to acknowledge that healthcare teams working in the NHS are working within limited resources and there may be limitations in what can be offered in this context.

5.6.2 Implications for clinical psychology

Along with considerations around communication and efficiency in planning appointments, additional implications for clinical psychology are offered. It is important for clinical psychologists to consider the social impact of managing both T1D and CD in a formulation of the young person’s difficulties (Carr, 2006b). It may be helpful to explore social barriers and challenges in managing a dual diagnosis of T1D and CD and support the development of problem-solving skills in managing social situations (Carr, 2006b; Christie, 2012). Young people with T1D and CD may benefit from discussions around thoughts and emotions associated with managing their conditions (Edwards & Titman, 2010). Engaging in problem-free talk and focussing discussions on aspects of the self that are not related to T1D or CD (Christie, 2012) may support integration of different aspects of the self. It is also important to recognise young people’s existing knowledge and strengths in managing either condition; it was found that knowledge and skills in managing T1D were also applicable to CD. Facilitating discussions and activities that might promote changing attitudes towards T1D and CD may also be helpful. Examples include focussing on the positive aspects of T1D and CD, considering what foods are available can be enjoyed and encourage experimenting with baking new foods with gluten-free ingredients.

There is a role in supporting young people and families in negotiating clear roles to facilitate a sense of independence for the young person with a dual diagnosis of T1D and CD (Christie, 2012). It may also be important to consider family culture and practices around eating to support inclusion at mealtimes. Dissemination of information about young people’s experiences and challenges associated with managing a dual diagnosis of T1D and CD with multi-disciplinary teams (Thompson et al. 2012) may enhance understanding and support therapeutic relationships with non-psychology healthcare professionals.
5.7 Future directions

This is the first known model to capture how young people manage a dual diagnosis of T1D and CD. However the current model may be limited to relatively positive experiences of managing of a dual diagnosis of T1D and CD. Further research is needed to explore young people’s experiences in the context of wider difficulties and challenges in managing both T1D and CD. The current model may be adapted and extended to take account of young people who report less successful management of a dual diagnosis of T1D and CD. Other areas that require further exploration include possible gender differences in young people’s experience of managing both T1D and CD, the impact of socio-economic status of families in managing a dual diagnosis of T1D and CD, and potential influences of different family cultures.

T1D and CD are both diet-related chronic health conditions and the current study suggested that strategies for managing T1D may be relevant and compatible with strategies for the management of CD. A novel finding in the current study was the impact of the timing of the diagnoses. For participants who were diagnosed at same time, diet-related strategies for managing T1D were considered applicable to the management of CD. For participants who were diagnosed with CD later, existing diet-related strategies for T1D were extended and adapted to support the management of CD. This may have an impact on how the dual diagnoses of T1D and CD is experienced and therefore warrants further investigation by future research. It is unclear whether this model would be applicable to dual diagnoses in other chronic health conditions that may have potentially less compatible strategies for self-management. Therefore further research regarding the model’s applicability to other areas of chronic health may also be beneficial.
6. References


Taler, I., Phillip, M., Lebenthal, Y., de Vries, L., Shamir, R. & Shalitin, S. (2012). Growth and metabolic control in participants with type 1 diabetes and celiac
disease: a longitudinal observational case-control study. *Pediatric Diabetes, 13*(8), 597-606.


doi:10.1097/MPG.0b013e31817fcb56

doi:dx.doi.org/10.2337/diacare.26.4.1079


Part Three

1. Critical Appraisal

1.1 Overview

I have selected to write this critical appraisal in the first person. It is based on my research journal completed throughout the research process. Critical reflections of my experiences of planning and carrying out the project and what I learned as researcher are discussed.

1.2 Developing the idea

On commencing clinical training I had a few ideas for research however I had no concept of how feasible they would be for a DClinPsy project. I did however approach the research project with two aims in mind: I wanted experience of completing a qualitative project and I wanted the outcome of the project to be meaningful, clinically relevant and helpful to my clinical psychology colleagues and other relevant healthcare professionals. During my first year I was very open to research ideas and enjoyed discussing research interests with academic tutors and local clinical psychologists. The current project really sparked my interest for a number of reasons; it was in the field of health psychology, an area I was not very familiar with, working with young people, a client group I had relatively little experience in working with, and it required a qualitative approach. Therefore I considered that the project offered a wealth of opportunities for learning. Through discussions with my field supervisors, I learned that the project aimed to address an area that was relatively under researched and was much needed to help inform clinical practice. Some might advise ‘stick to what you know’ but I was very keen to learn and I wanted to get the most out of my training experience.

1.3 Epistemological position

Ontology and epistemology were concepts I had thought very little about or considered in relation to research prior to training. My research experiences had been somewhat biased toward positivist and realist perspectives with a heavy focus on quantitative research for my undergraduate and master’s degrees. My main concerns in designing and
carrying out quantitative research had been around maintaining objectivity and scientific rigour. At that point, qualitative research was an elusive method that I had very little understanding of and no experience with. It is interesting looking back on these experiences; I had taken part in many undergraduate studies during my time at university, all quantitative projects, and I can recall thinking to myself ‘it’s an interesting idea, but they’re not getting the whole picture’. Even then, I knew the limitations of using quantitative methods however I had never fully connected with what qualitative methods could offer.

Reflecting back, I think I have always taken a constructionist epistemological perspective. I just didn’t really think about it and I have never had to name or define it until now. I can recall family discussions where swift judgements were often made about scenarios or people and I would often interject with ‘yes, but we don’t know the full story’, ‘well you don’t know what they’ve been through’, and ‘well it depends on how other people they see it.’ So when I started reading about constructionist perspectives, the view that social realities are co-constructed through social interactions with others, it was an idea I really connected with. I think having this perspective and learning of Charmaz’s constructionist approach to grounded theory gave me the confidence I needed to embark on this project.

1.4 Designing the study

The aim of the study was always to explore, in depth, young people’s experiences of managing a dual diagnosis of T1D and CD, therefore a qualitative approach was an appropriate method. However quantitative methods could have been used to explore the impact of T1D and CD. Questionnaires could have been designed to assess coping styles or quality of life in T1D and CD however this would have required significant adaptations to the study aims and research question. Equally a quantitative design would not have generated detailed responses and rich information about young people’s experiences and specifically how they manage both T1D and CD. It would not have allowed us to take an in depth look at what the main concerns and challenges are for young people living with a dual diagnosis of T1D and CD, information that was considered key in informing clinical practice.
Having decided on a qualitative project, discussions with research and field supervisors confirmed to me that interviewing young people about their experiences would be the most appropriate form of data collection and generation. We could have used focus groups however as we were interested in the experiences of adolescents, I considered that participants being involved in discussions with their peers may have influenced the discussions about managing T1D and CD.

We initially considered using IPA methodology as it would have facilitated exploration of lived experiences and one of my field supervisors had experience of using this method. However on completing my literature review in this area, I discovered a similar project completed by a trainee at another institution in the preceding year. Although this wasn’t an issue; the aims of the previous study were slightly different to the current study, this did prompt me to reconsider the design of the study and revisit other qualitative options. I returned to reading about different methods and it became clear that grounded theory was the method for me. I had noticed that as we had been developing the idea and thinking about the project aims and questions, I found myself being drawn to questions that were not necessarily focussed around experience, but rather more specifically about how young people manage T1D and CD? What is it that young people are doing to cope with the complexity of managing two chronic health conditions? The more I read by Corbin and Strauss (2008) and Charmaz (2006) the more I realised that grounded theory would equip me in answering these questions.

1.5 Ethical Approval

Applying for ethical approval and going through this process was a valuable experience for me. Prior to this I had no idea what the expectations were or the typical timescales for gaining ethical approval and local management approval in the NHS. If I’m honest, I had anticipated the process to be very convoluted, time consuming, and unpleasant. However having now had the experience myself, I have learned much and I feel confident about doing it again. I had prepared well, submitted a detailed application form, and attended a meeting with the ethics committee to answer any questions. Ethical approval was granted with few problems and I was surprised at how quickly the committee arrived at a decision about the project. However I did underestimate the amount of time it would then take to
gain local NHS management approval for the study. I also learned that this can vary wildly between different trusts. Based on my experiences I am now aware of the need to apply early, keep track of the progress of your application, and the importance of building relationships with local research and development teams within the trusts that you are working.

1.6 Recruitment strategy

Recruitment through healthcare professionals in diabetes teams and paediatric psychology teams was considered the best approach due to small numbers of young people with a dual diagnosis of T1D and CD. This appeared to be the most reliable and ethical way to recruit participants. Another option would have been to advertise the research project on relevant notice boards and websites, however this was likely to have resulted in a very low response rate.

I had heard from fellow trainees that recruitment is often the biggest challenge to any study. Despite this, I hadn’t anticipated the recruitment stage of the current study to be as challenging as it was. Initial discussions with the diabetes team suggested that staff were on board with the project and keen to support me with recruitment. However twelve months then passed as ethical approval for the project was being sought. I do feel that this passage of time dissolved any enthusiasm and momentum I had generated in those initial meetings. When the time eventually came to commence recruitment, I was met with some trepidation and uncertainty about whether it was possible for me to reach my recruitment targets. I realised the pressures and demands being placed on healthcare teams in the NHS and this helped me contextualise their response. Developing positive relationships with the teams through understanding and empathy with their position enabled us to engage in problem-solving and reach a compromise on the recruitment strategies we had discussed. Rather than healthcare professionals disseminating information packs during appointments, we agreed to post out information packs to all eligible young people. I agreed to attend clinics and be on hand to discuss the project with families that expressed an interest. I valued input from the doctors and nurses in the teams; hearing their ideas and working collaboratively with them helped the project move forward.
As the research progressed, I encountered difficulties recruiting enough participants from the initial diabetes and paediatric psychology teams due to small numbers of young people with both diagnoses, and some young people transitioning to an adult clinic. Therefore a second site was added in December 2015 to maximise recruitment. This was another diabetes outpatient service located in an adjacent NHS trust. I was lucky in that recruiting from this second site went without a hitch; the Consultant Paediatrician was very much on board with the project. Through my experience of recruiting through medical teams, I learned that building relationships, maintaining open communication with teams, and being clear about what it is you are asking of teams would be helpful in future research collaborations.

1.7 Interviewing and generating data

I was anxious about interviewing young people, especially teenagers. Although I was a teenager once myself, I did wonder how I would be perceived by the young people I interviewed. Equally I’m sure they wondered about what I thought of them. It is possible that the very nature of ‘interviewing’ someone about their experiences influences what is disclosed and how this is communicated. It is natural in any social situation to want to make a good impression. Participants varied in their style and presentation; some young people were confident and talkative, others were very quiet and gave quite short responses. At times I found I had to work quite hard to get the conversation going. I found that I was able to draw on my clinical experience of working with clients from a range of backgrounds to help participants feel at ease and able to engage with the interview. Another challenge was managing interruptions from parents and family and my equipment failing. I found that participants responded best to my being light-hearted and using humour in these situations.

One of my main concerns was about maintaining a balance between asking questions about the areas I was interested in and being open to what the participant wanted to offer in terms of their experience. My aim was to generate good quality data for analysis. I was also aware of the need to keep reflections and summaries to a minimum to minimise the potential for me to offer my own interpretations during the interview. However I did
summarise briefly at times to clarify that I understood what the participant was communicating.

In earlier interviews I noticed that I was open to all the information participants could offer me. In later interviews, I was more focussed on asking questions around the categories I was developing, however I was careful to not appear as if I was imposing these questions on participants during interview. Interestingly, similar themes in early interviews emerged in later interviews without too much probing which explicated the categories nicely.

Organising the timing of interviews was paramount in ensuring the GT methods were applied appropriately. I needed to ensure enough time in between interviews for transcription and coding to inform the next interview. This required planning, organisation, and discipline on my part. I allowed between 10-14 days in between interviews which although was challenging at times, it worked well for me given the timescales I was working with in order to have the project completed by April 2016.

1.8 Transcribing interviews

I had made a decision early on that I wanted the experience of transcribing my own interviews. This was partly to facilitate immersion in the data and partly to support me in developing skills in transcribing. I considered myself to be technically competent and wondered ‘how hard can it be?’

I discovered that transcribing interviews took much longer than anticipated. The use of a pedal to control the playback of the audio file along with transcription software helped speed up the process however I continued to struggle. I was working under tight time constraints, and due to the nature of the GT method, I required each interview to be transcribed and coded before the next one. After the first four interviews I decided to get help from a professional and outsourced transcriptions services for the remaining four transcripts. I found that having interviews transcribed elsewhere did not adversely impact on my becoming immersed in the data. Although an experience I’m very pleased to have had, my own view on transcribing has somewhat shifted. If I was planning a project that required a significant number of interviews, limited time, and the resources to outsource transcription services, I think I would probably choose this option in the future.
1.9 Analysis and data interpretation

Whilst I was initially excited by using the grounded theory method, when I started analysis I was quickly overwhelmed. At times I wondered if I really understood the method, if I was doing it ‘right’ and if I even had enough time to do it justice.

I had read about GT as described by both Corbin and Strauss (2008) and Charmaz (2006) and I was anxious about how the methods would translate into my own research. I found myself wanting to fully understand everything before starting my own analysis. However I quickly realised that this was unrealistic due to time constraints and that it might not have been the most effective way to learn. I now consider that although a foundation knowledge of GT and preparation is important, GT is a method that you can only fully appreciate through doing it.

Through my experience of conducting qualitative research, I have discovered that I can be quite a rigid thinker and that GT requires a more flexibility and creativity than I had anticipated. At times I felt anxious and concerned about the decisions I was making and the directions in which I was taking the analysis. I found memo writing invaluable in helping me process my thoughts and recognise when my own preconceptions might have been influencing the data. Whilst at times being overwhelmed by the volume of data that the analysis generated, I also found it hard to let go of information that was less relevant and maintain a focus on the main concerns, patterns, and themes I had gleaned from the data. I did find that this got better with practice.

I found using some of the tools described by Corbin and Strauss (2008) to be helpful such as the ‘flip-flop’ technique, helping you to see concepts and processes from different perspectives and ‘waving the red flag’ recognising when your own preconceptions were influencing the interpretation. An example of this was that initially, I noticed a tendency for me to minimise the level of support participants accessed from family relationships. I reflected on this through memo writing and once I had acknowledged this influence I was able to ‘bracket’ this and continue with the analysis. I went back to the data with this fresh perspective to find that although participants were very keen to communicate their independence, it became clear that family relationships were a vital platform for the development of this independence. This really highlighted to me the constructionist
aspect of GT, and the implication of how different researchers, completing this project in a different contexts, might have generated alternative interpretations.

1.10 Supervision

I accessed research supervision from a range of sources including my academic supervisors, my field supervisors, and fellow trainees undertaking qualitative research. Supervision was vital in supporting me to maintain quality in using grounded theory methods. Regular research meetings with my academic and field supervisors enabled me to reflect on concepts, codes, and categories, to ensure ‘fit’ with the data. I also appreciated the space in supervision to discuss times when I felt confused or lost in the analysis. I also valued sharing experiences and ideas with fellow trainees conducting qualitative research in other unrelated topics. I attended a regular qualitative research group. On a few occasions we took the opportunity to code each other’s transcripts. When comparing our codes we noticed how each of our methods was informing the types of codes we were generating. I was very much interested in what was happening in the data, what processes were taking place and the social interactions described by participants. This was reflected in my codes which were often gerunds or ‘doing words’. My colleague, who was using IPA, was very much focussed on the meaning of the experiences my participants were describing and was therefore coding for this. Her codes appeared to reflect the participants feelings more than mine. However when comparing the essence of the codes and the pertinent themes that were identified for each of us, we did note that although we conceptualised the information differently, the underlying concepts were very similar. This reassured me that what I was seeing in the data, the main concerns or concepts, were also being recognised by others. This was a good exercise that not only helped me learn about my own approach to my research, but also how this might be different to the approach of another trainee adopting a different qualitative method.

1.11 Conclusions

I have learned a great deal from completing this research project and I have found it to be an inspiring and enriching experience. It has given me the skills and confidence to take
on research projects in the future as a qualified clinical psychologist. I have learned to appreciate the challenges of undertaking research in a clinical context.

Based on my experiences, I now consider some of the key factors in conducting a successful research project are; collaborating with others, developing relationships, recruiting other professionals to become involved and invested in the research idea and its potential outcomes, being organised, maintaining open communication, providing regular updates to those involved, and accessing support and supervision regularly to maintain momentum and enthusiasm for the project through to completion. Having had this experience, I feel I have a better idea of how to approach and plan research projects and how to manage barriers and challenges that may arise. But most importantly I have discovered that the value of undertaking research in a clinical context far outweighs the challenges that might accompany it.
2. References


Appendices

Appendix A – Author Guidelines

Journal targeted for the Literature Review: British Journal of Health Psychology

Author Guidelines

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology as outlined in the Journal Overview.

The types of paper invited are:

- papers reporting original empirical investigations, using either quantitative or qualitative methods, including reports of interventions in clinical and non-clinical populations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- we particularly welcome review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and
- methodological papers dealing with methodological issues of particular relevance to health psychology.

All papers published in The British Journal of Health Psychology are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words (excluding the abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:
• the content of the paper falls within the scope of the Journal
• the methods and/or sample size are appropriate for the questions being addressed
• research with student populations is appropriately justified
• the word count is within the stated limit for the Journal (i.e. 5000 words)

4. Submission and reviewing

All manuscripts must be submitted via Editorial Manager. You may like to use the Submission Checklist to help you prepare your manuscript. The Journal operates a policy of anonymous peer review. Authors must suggest three reviewers when submitting their manuscript, who may or may not be approached by the Associate Editor dealing with the paper. Before submitting, please read the terms and conditions of submission and the declaration of competing interests.

5. Manuscript requirements

• Contributions must be typed in double spacing with wide margins. All sheets must be numbered.

• Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author’s contact details. A template can be downloaded from here.

• For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions. As the abstract is often the most widely visible part of your paper, it is important that it conveys succinctly all the most important features of your study. You can save words by writing short, direct sentences. Helpful hints about writing the conclusions to abstracts can be found here.

• Statement of Contribution: All authors are required to provide a clear summary of ‘what is already known on this subject?’ and ‘what does this study add?’. Authors should identify existing research knowledge relating to the specific research question and give a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 (maximum) clear outcome statements (not process statements of what the paper does); the statements for 'what does this study add?' should be presented as bullet points of no more than 100 characters each. The Statement of Contribution should be a separate file.

• Conflict of interest statement: We are now including a brief conflict of interest statement at the end of each accepted manuscript. You will be asked to provide information to generate this statement during the submission process.

• The main document must be anonymous. Please do not mention the authors’ names or affiliations (including in the Method section) and always refer to any previous work in the third person.
• Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.

• Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.

• For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide doi numbers where possible for journal articles. For example:


• SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.

• In normal circumstances, effect size should be incorporated.

• Authors are requested to avoid the use of sexist language.

• Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.

• Manuscripts describing clinical trials are encouraged to submit in accordance with the CONSORT statement on reporting randomised controlled trials.

• Manuscripts reporting systematic reviews and meta-analyses are encouraged to submit in accordance with the PRISMA statement.

• Manuscripts reporting interventions are encouraged to describe them in accordance with the TIDieR checklist.

6. Supporting information

Supporting Information can be a useful way for an author to include important but ancillary information with the online version of an article. Examples of Supporting Information include appendices, additional tables, data sets, figures, movie files, audio clips, and other related nonessential multimedia files. Supporting Information should be cited within the article text, and a descriptive legend should be included. Please indicate clearly on submission which material is for online only publication. It is published as supplied by the author, and a proof is not made available prior to publication; for these reasons, authors should provide any Supporting Information in the desired final format.
For further information on recommended file types and requirements for submission, please visit the Supporting Information page on Author Services.

7. OnlineOpen

OnlineOpen is available to authors of primary research articles who wish to make their article available to non-subscribers on publication, or whose funding agency requires grantees to archive the final version of their article. With OnlineOpen, the author, the author's funding agency, or the author's institution pays a fee to ensure that the article is made available to non-subscribers upon publication via Wiley Online Library, as well as deposited in the funding agency's preferred archive. A full list of terms and conditions is available on Wiley Online Library.

Any authors wishing to send their paper OnlineOpen will be required to complete the payment form.

Prior to acceptance there is no requirement to inform an Editorial Office that you intend to publish your paper OnlineOpen if you do not wish to. All OnlineOpen articles are treated in the same way as any other article. They go through the journal's standard peer-review process and will be accepted or rejected based on their own merit.

8. Author Services

Author Services enables authors to track their article – once it has been accepted – through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key stages of production. The author will receive an e-mail with a unique link that enables them to register and have their article automatically added to the system. You can then access Kudos through Author Services, which will help you to increase the impact of your research. Visit Author Services for more details on online production tracking and for a wealth of resources including FAQs and tips on article preparation, submission and more.

9. Copyright and licences

If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services, where via the Wiley Author Licensing Service (WALS) they will be able to complete the licence agreement on behalf of all authors on the paper.

For authors signing the copyright transfer agreement

If the OnlineOpen option is not selected the corresponding author will be presented with the copyright transfer agreement (CTA) to sign. The terms and conditions of the CTA can be previewed in the samples associated with the Copyright FAQs.

For authors choosing OnlineOpen

If the OnlineOpen option is selected the corresponding author will have a choice of the following Creative Commons Licence Open Access Agreements (OAA):
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To preview the terms and conditions of these open access agreements please visit the Copyright FAQs and you may also like to visit the Wiley Open Access Copyright and Licence page.

If you select the OnlineOpen option and your research is funded by The Wellcome Trust and members of the Research Councils UK (RCUK) or the Austrian Science Fund (FWF) you will be given the opportunity to publish your article under a CC-BY licence supporting you in complying with your Funder requirements. For more information on this policy and the Journal’s compliant self-archiving policy please visit our Funder Policy page.

10. Colour illustrations

Colour illustrations can be accepted for publication online. These would be reproduced in greyscale in the print version. If authors would like these figures to be reproduced in colour in print at their expense they should request this by completing a Colour Work Agreement form upon acceptance of the paper.

11. Pre-submission English-language editing

Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. A list of independent suppliers of editing services can be found in Author Services. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

12. The Later Stages

The corresponding author will receive an email alert containing a link to a web site. The proof can be downloaded as a PDF (portable document format) file from this site. Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from Adobe’s web site. This will enable the file to be opened, read on screen and annotated direct in the PDF. Corrections can also be supplied by hard copy if preferred. Further instructions will be sent with the proof. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately.

13. Early View

British Journal of Health Psychology is covered by the Early View service on Wiley Online Library. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Articles are therefore available as soon as they are ready, rather than having to wait for the next scheduled print issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors’ final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View
articles means that they do not yet have volume, issue or page numbers, so they cannot be cited in the traditional way. They are cited using their Digital Object Identifier (DOI) with no volume and issue or pagination information. Eg Jones, A.B. (2010). Human rights Issues. *Journal of Human Rights*. Advance online publication. doi:10.1111/j.1467-9299.2010.00300.x
### Appendix B – Search Strategy

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|                     | 2. exp INSULIN DEPENDENT DIABETES MELLITUS/  
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|                     | 5. (diabetes ADJ2 "type I").ti,ab,af  
|                     | 6. ("insulin dependent diabetes" OR "insulin-dependent diabetes").ti,ab,af  
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|                     | 26. 7 AND 13 AND 26  
|                     | 27. 32 [Limit to: Human and English Language and (Publication Types Article)]  
| MEDLINE 108 results | 1. exp Diabetes Mellitus, Type 1/  
|                     | 2. ("insulin? dependent diabetes" or "insulin?dependent diabetes").mp.  
|                     | 3. ((type 1 or type I) adj2 diabetes).mp  
|                     | 4. ("T1D" or "T1DM" or "IDDM").mp.  
|                     | 5. 1 or 2 or 3 or 4 or 5  
|                     | 6. exp Celiac Disease/  
|                     | 8. ("gluten?sensitive enteropathy" or "gluten? sensitive enteropathy").mp.  
|                     | 9. 7 or 8 or 9 or 10  
|                     | 10. psych$.mp.  
|                     | 11. ("wellbeing" or "well-being" or "well being").mp.  
|                     | 12. exp "Quality of Life"/  
|                     | 13. ("quality of life" or "QoL").mp.  
|                     | 15. "depress$".mp.  
|                     | 17. exp Anxiety/  
|                     | 18. exp Depression/  
|                     | 19. exp Emotions/  
|                     | 20. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21  
|
21. 6 and 11 and 22
22. Limit 23 to English language

| PSYCHINFO          | 1. DE "Diabetes" OR DE "Diabetes Mellitus"
|                    | 2. TX "type 1 diabetes"
|                    | 3. TX "type I diabetes"
|                    | 4. TX "diabetes type 1"
|                    | 5. TX "diabetes type I"
|                    | 6. TX "insulin dependent diabetes"
|                    | 7. TX "T1D" or "T1DM" or "IDDM"
|                    | 8. S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7
|                    | 9. TX "celiac disease"
|                    | 10. TX "gluten sensitive enteropathy"
|                    | 11. S10 OR S11 OR S12
|                    | 12. S9 AND S13
|                    | 13. Limit to English, academic journals

| CINAHL             | 1. (MH "Diabetes Mellitus, Type 1+")
|                    | 2. insulin-dependent diabetes
|                    | 3. type 1 N2 diabetes
|                    | 4. type I N2 diabetes
|                    | 5. "T1D" or "T1DM" or "IDDM"
|                    | 6. S1 OR S2 OR S3 OR S4 OR S5
|                    | 7. (MH "Celiac Disease+")
|                    | 8. "celiac disease"
|                    | 9. "gluten sensitive enteropathy"
|                    | 10. S8 OR S9 OR S10
|                    | 11. psych*
|                    | 12. "well being" or "wellbeing"
|                    | 13. "quality of life" or "QoL"
|                    | 14. (MH "Quality of Life+")
|                    | 15. (MH "Anxiety+")
|                    | 16. anxiety
|                    | 17. (MH "Depression+")
|                    | 18. depression
|                    | 19. emotion*
|                    | 20. (MH "Psychology, Social+")
|                    | 21. S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20
|                    | 22. S6 AND S10 AND S21
|                    | 23. Limit to English language, academic journals
### Appendix C – Inclusion/exclusion criteria (Literature Review)

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Study reports on aspects of both T1D and CD</td>
<td>• Not published in English.</td>
</tr>
<tr>
<td>• Study includes a measure of psychological or social functioning.</td>
<td>• Reported prevalence rates of T1D and/or CD only</td>
</tr>
<tr>
<td></td>
<td>• Reported links between other physical illnesses only</td>
</tr>
<tr>
<td></td>
<td>• Reported on screening exercises only</td>
</tr>
<tr>
<td></td>
<td>• Not an original article (e.g. review, letter, editorial, research proposal, conference abstracts)</td>
</tr>
<tr>
<td></td>
<td>• Qualitative research articles</td>
</tr>
</tbody>
</table>
# Appendix D – Data Extraction Form

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Author / Year</td>
<td></td>
</tr>
<tr>
<td>Title</td>
<td></td>
</tr>
<tr>
<td>Origin</td>
<td></td>
</tr>
<tr>
<td>Setting</td>
<td></td>
</tr>
<tr>
<td>Objectives</td>
<td></td>
</tr>
<tr>
<td>Sample</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td>Inclusion criteria</td>
<td></td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td></td>
</tr>
<tr>
<td>Comparison group?</td>
<td></td>
</tr>
<tr>
<td>Outcome measures</td>
<td></td>
</tr>
<tr>
<td>Analysis</td>
<td></td>
</tr>
<tr>
<td>Conclusions</td>
<td></td>
</tr>
<tr>
<td>Limitations</td>
<td></td>
</tr>
</tbody>
</table>
### Appendix E - STROBE Checklist

STROBE Statement—checklist of items that should be included in reports of observational studies

<table>
<thead>
<tr>
<th>Item No</th>
<th>Item</th>
<th>Recommendation</th>
</tr>
</thead>
</table>
| **Title and abstract** 1 | (a) Indicate the study’s design with a commonly used term in the title or the abstract  
(b) Provide in the abstract an informative and balanced summary of what was done and what was found |
| **Introduction** | | |
| **Background/rationale** 2 | Explain the scientific background and rationale for the investigation being reported |
| **Objectives** 3 | State specific objectives, including any prespecified hypotheses |
| **Methods** | | |
| **Study design** 4 | Present key elements of study design early in the paper |
| **Setting** 5 | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection |
| **Participants** 6 | (a) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up  
Case-control study—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls  
Cross-sectional study—Give the eligibility criteria, and the sources and methods of selection of participants  
(b) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed  
Case-control study—For matched studies, give matching criteria and the number of controls per case |
| **Variables** 7 | Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable |
| **Data sources/measurement** 8 | For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group |
| **Bias** 9 | Describe any efforts to address potential sources of bias |
| **Study size** 10 | Explain how the study size was arrived at |
| **Quantitative variables** 11 | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why |
| **Statistical methods** 12 | (a) Describe all statistical methods, including those used to control for confounding  
(b) Describe any methods used to examine subgroups and interactions  
(c) Explain how missing data were addressed  
(d) *Cohort study*—If applicable, explain how loss to follow-up was addressed  
Case-control study—If applicable, explain how matching of cases and controls was addressed  
Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy  
(e) Describe any sensitivity analyses |

Continued on next page
| Results |
|------------------|------------------|
| Participants | 13*  |
| (a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed  |
| (b) Give reasons for non-participation at each stage  |
| (c) Consider use of a flow diagram  |
| Descriptive data | 14*  |
| (a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders  |
| (b) Indicate number of participants with missing data for each variable of interest  |
| (c) Cohort study—Summarise follow-up time (eg, average and total amount)  |
| Outcome data | 15*  |
| Cohort study—Report numbers of outcome events or summary measures over time  |
| Case-control study—Report numbers in each exposure category, or summary measures of exposure  |
| Cross-sectional study—Report numbers of outcome events or summary measures  |
| Main results | 16  |
| (a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included  |
| (b) Report category boundaries when continuous variables were categorized  |
| (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period  |
| Other analyses | 17  |
| Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses  |

Discussion

Key results | 18  |
| Summarise key results with reference to study objectives  |

Limitations | 19  |
| Discuss limitations of the study, taking into account sources of potential bias or imprecision  |
| Discuss both direction and magnitude of any potential bias  |

Interpretation | 20  |
| Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence  |

Generalisability | 21  |
| Discuss the generalisability (external validity) of the study results  |

Other information

Finding | 22  |
| Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based  |

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Appendix F - Researcher perspective and epistemological position

**Researcher perspective and epistemological position**

A researcher’s epistemological position is informed by two assumptions about the world; the theory of reality (ontology) and the theory of knowledge (epistemology). A researcher’s epistemological position informs the type of research they engage in and how it might be designed (Chamberlain, 2015).

The researcher in the current study adopted a ‘contextual constructionist’ (Madill et al. 2000) position congruent with their own personal views and beliefs about the world. This position assumes the existence of multiple realities and that knowledge is dependent upon the context in which the researcher and participant are situated. Constructivist grounded theory methodology assumes that knowledge is co-constructed by the participants and the researcher in context (Charmaz, 2006), therefore this methodology was selected in line with the researcher’s own epistemological position.

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Appendix G – Chronology of the research process

<table>
<thead>
<tr>
<th>Month/Year</th>
<th>Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>June 2014</td>
<td>Research Panel Review of Research Proposal</td>
</tr>
<tr>
<td>Aug 2014</td>
<td>Amendments to Research Proposal</td>
</tr>
<tr>
<td>Sep 2014</td>
<td>Peer Review of Research Proposal</td>
</tr>
<tr>
<td>Oct 2014</td>
<td>Lay Summary submitted to Service User Research</td>
</tr>
<tr>
<td>March 2015</td>
<td>Application for Ethical Approval</td>
</tr>
<tr>
<td>April 2015</td>
<td>Ethical approval granted</td>
</tr>
<tr>
<td>April 2015</td>
<td>Submitted application for local NHS management approval</td>
</tr>
<tr>
<td>September</td>
<td>Local management approval gained from first NHS site</td>
</tr>
<tr>
<td>October 2015</td>
<td>Released information packs to teams</td>
</tr>
<tr>
<td>October 2015</td>
<td>Commenced recruitment, screening, scheduling</td>
</tr>
<tr>
<td>November</td>
<td>Commenced interviews / data collection</td>
</tr>
<tr>
<td>November</td>
<td>Commenced data analysis</td>
</tr>
<tr>
<td>December</td>
<td>Application for local NHS management approval for second site</td>
</tr>
<tr>
<td>January 2016</td>
<td>Local management approval gained from second NHS site</td>
</tr>
<tr>
<td>March 2016</td>
<td>Finish data analysis and write-up</td>
</tr>
<tr>
<td>May 2016</td>
<td>Hand in final thesis</td>
</tr>
<tr>
<td>August 2016</td>
<td>Dissemination of results to stakeholders/teams</td>
</tr>
</tbody>
</table>
Would you be interested in taking part in a research project about young people's experiences of living with Type 1 Diabetes and Coeliac Disease?

Part 1

Study Title

Young people’s experiences of living with Type 1 Diabetes and Coeliac Disease.

Invitation paragraph

Hello! We are inviting you to take part in a research project. Before you decide if you would like to take part, it is important for you to know why the research is being done and what you will need to do to take part. This leaflet will tell you more.

Who are we?

My name is Nathalie Gray, and I am a student at the university. I am completing this research project as part of my training in clinical psychology. I am being supervised by Mrs Mary O’Reilly, Dr Camilla Watters, and Dr Amandeep Samrai. They make sure I am doing the project in the right way.

What is our research about?

We are hoping to find out about the experiences of young people like you, who are with living with type 1 diabetes and coeliac
disease. We are interested in hearing about the time when you were told about your conditions, how you feel about it, and how things are at home and school for you now.

**Why are we doing this research?**
We want to understand what it is like for young people living with both type 1 diabetes and coeliac disease. We also hope that the research will help us think about better ways that doctors, nurses and medical teams can support you in living with both conditions.

**Why have I been asked to take part?**
You have been chosen because you are a young person living with type diabetes and coeliac disease. We are hoping to interview about 8 to 10 young people aged between 11-18 years with type 1 diabetes and coeliac disease.

**Do I have to take part?**
No. It is up to you to decide if you want to take part. If you do decide to take part, I will give you this booklet to keep and I will ask you to sign a consent form.

**What will happen if I do take part?**
You will be invited to come to and talk to me at NHS sites such as the Leicester Royal Infirmary. It might be possible for some interviews to be done at home. I will be asking you some general questions and you will have the chance to talk about things like when you were told about your type 1 diabetes and coeliac disease, and what kind of things you do every day. I will only ask short, general questions; you can say as much as you want. The interview should take between 1 hour to 1 hour and a half. I will tape the sessions so that I can write down exactly what you say, and exactly what I say. I will be looking for the similarities and differences in what young people say.
Are there any advantages to taking part in the study?
We are not offering any kind of treatment. However, if you choose to take part you will have a chance to help us understand what it is like for young people living with both type 1 diabetes and coeliac disease. We hope that this research will be published and make a difference to how young people are supported in managing both conditions. We are also offering a £10.00 Amazon or ITunes voucher as a ‘thank you’ for taking part.

What are the possible disadvantages?
You may find the interviews distressing. We do not expect you to talk about times that were upsetting for you and you can stop the interview at any time. We can contact your parents at any time during the interview if you need them.

Contact for further information
Nathalie Gray (Trainee Clinical Psychologist)
Email: nk204@le.ac.uk
Address: University of Leicester
104 Regent Road
Leicester
LE1 7LT
Telephone: 0116 223 1639

Camilla Watters (Consultant Clinical Psychologist)
Address: Department of Paediatric Psychology
c/o Westcotes House
Westcotes Drive
Leicester LE3 0QU
Telephone: 0116 295 2959

Thank you for reading so far - if you are still interested, please go to Part 2.
Part 2 more detail – information you need to know if you still want to take part:

Will you tell anyone what I say?
No. All the answers you give will be kept private. However, if you tell me that you or someone else in your family is in getting hurt or may get hurt, I will have to tell my supervisor. My supervisor will decide what to do with that information to make sure that you are kept safe.

What if I don’t want to do the research anymore?
Just tell your mum, dad, carer, doctor or nurse at any time. They will not be cross with you. You will still have the same care and treatment. If you change your mind after you have completed the interview, you will need to let us know before 1st November 2015 so that we can remove your information from the study.

What if there is a problem or something goes wrong?
Tell us if there is a problem and we will try and sort it out straight away. You and your mum and dad can either contact the:

Project co-ordinator:
Nathalie Gray (Trainee Clinical Psychologist)
University of Leicester
104 Regent Road
Leicester
LE1 7LT
Email: nk204@le.ac.uk
Telephone: 0116 223 1639

Or the Patient Information and Liaison Services
University Hospitals of Leicester
Patient Information and Liaison Service
Will anyone else know I’m doing this?

The people in our research team will know you are taking part. The treatment team helping you with your diabetes and coeliac disease will also know. All information that is collected about you during the research will be kept strictly confidential. You will be given a number which will be used instead.

Any information about you that leaves the hospital will have your name and address removed so that you cannot be recognised from it. Once the study is complete all information will kept for 5 years or after then it will be destroyed.
What will happen to the results of this study?
When the study has finished I will present the findings to other doctors, and we will put the results in medical and psychology magazines and websites that doctors read. I may use some sentences from my interviews with you. I will change names and places so that no-one should be able to work out that it was your sentence that I used. The results will also be included as part of my educational qualification.

Who is organising and funding the research?
Clinical Psychologists within the Paediatric Psychology Service and myself, a researcher at the University of Leicester are organising this study. They will not get any extra money for doing this research. The research is being paid for by the University of Leicester.

Who has checked the study?
Before any research goes ahead it has to be checked by a Research Ethics Committee. This is a group of people who make sure that the research is OK to do. This study has been looked at by Northampton Research Ethics Committee. It has also been checked by the Research Department at the University of Leicester, Leicestershire Partnership NHS Trust, and University Hospitals of Leicester NHS Trust.

How can I find out more about research?
The University Hospitals of Leicester has information about research on its website:

http://www.leicestershospitals.nhs.uk/aboutus/education-and-research/

To find out more about research and development at Leicestershire Partnership NHS Trust please visit:

Thank you for taking the time to read this.

Any questions?
We would be really pleased if you decided to take part in this research. If you would like further information, you can contact us using the contact details in this leaflet.

If you would like to express an interest in taking part, please complete the slip on the bottom of the page, detach the slip along the dotted line, and return using the enclosed stamped addressed envelope.

Thank you!

Expression of Interest

Young people’s experiences of living Type 1 Diabetes and Coeliac Disease

I would like to express an interest in taking part in the research project exploring young people’s experiences of living with Type 1 Diabetes and Coeliac Disease. By providing my contact details below, I consent to being contacted by the researcher to discuss suitability and potential participation in the research project.

Name of Young Person: ___________________________________________________
Name of Parent: _______________________________________________________
Address: ______________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
Telephone number: _____________________________________________________
Email: _________________________________________________________________

I prefer to be contacted by (please tick) ☐ Telephone ☐ Email ☐ Post

PLEASE RETURN USING ENCLOSED SAE TO: Nathalie Gray, University of Leicester, 104 Regent Road, Leicester, LE1 7LT

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Appendix I – Participant Information Sheet (16-18 years)

Young Person Information Sheet (16-18 Years)

Would you be interested in taking part in a research project about young people's experiences of living with Type 1 Diabetes and Coeliac Disease?

Part 1

Study Title

Young people’s experiences of living with Type 1 Diabetes and Coeliac Disease.

Invitation paragraph

Hello! We are inviting you to take part in a research project. Before you decide if you would like to take part, it is important for you to know why the research is being done and what you will need to do to take part. This leaflet will tell you more.

Who are we?

My name is Nathalie Gray, and I am a student at the university. I am completing this research project as part of my training in clinical psychology. I am being supervised by Mrs Mary O’Reilly, Dr Camilla Watters, and Dr Amandeep Samrai. They make sure I am doing the project in the right way.

What is our research about?

We are hoping to find out about the experiences of young people like you, who are with living with type 1 diabetes and coeliac disease. We are interested in hearing
about the time when you were told about you conditions, how you feel about it, and how things are at home and school for you now.

**Why are we doing this research?**

We want to understand what it is like for young people living with both type 1 diabetes and coeliac disease. We also hope that the research will help us think about better ways that doctors, nurses and medical teams can support you in living with both conditions.

**Why have I been asked to take part?**

You have been asked to take part because you are a young person living with type diabetes and coeliac disease. We are hoping to interview about 8 to 10 young people aged between 11-18 years with type 1 diabetes and coeliac disease.

**Do I have to take part?**

No. It is up to you to decide if you want to take part. If you do decide to take part, I will give you this booklet to keep and I will ask you to sign a consent form.

**What will happen if I do take part?**

You will be invited to come to and talk to me at NHS sites such as the Leicester Royal Infirmary. It might be possible for some interviews to be done at home. I will be asking you some general questions and you will have the chance to talk about things like when you were told about your type 1 diabetes and coeliac disease, and what kind of things you do every day. I will only ask short, general questions; you can say as much as you want. The interview should take between 1 hour to 1 hour and a half. I will tape the sessions so that I can write down exactly what you say, and exactly what I say. I will be looking for the similarities and differences in what young people say.
Are there any advantages to taking part in the study?
We are not offering any kind of treatment. However, if you choose to take part you will have a chance to help us understand what it is like for young people living with both type 1 diabetes and coeliac disease. We hope that this research will be published and make a difference to how young people are supported in managing both conditions. We are also offering a £10.00 Amazon or ITunes voucher as a ‘thank you’ for taking part.

What are the possible disadvantages?
You may find the interviews distressing. We do not expect you to talk about times that were upsetting for you and you can stop the interview at any time. We can contact your parents at any time during the interview if you need them.

Contact for further information
Nathalie Gray (Trainee Clinical Psychologist)
Email: nk204@le.ac.uk
Address: University of Leicester
104 Regent Road
Leicester
LE1 7LT

Dr Camilla Watters (Consultant Clinical Psychologist)
Address: Department of Paediatric Psychology
c/o Westcotes House
Westcotes Drive
Leicester LE3 0QU
Telephone: 0116 295 2959

Thank you for reading so far - if you are still interested, please go to Part 2.
**Part 2 more detail – information you need to know if you still want to take part:**

**Will you tell anyone what I say?**
No. All the answers you give will be kept private. However, if you tell me that you or someone else in your family is in getting hurt or may get hurt, I will have to tell my supervisor. My supervisor will decide what to do with that information to make sure that you are kept safe.

**What if I don’t want to do the research anymore?**
Just tell your mum, dad, carer, doctor or nurse at any time. They will not be cross with you. You will still have the same care and treatment. If you change your mind after you have completed the interview, you will need to let us know before 1st November 2015 so that we can remove your information from the study.

**What if there is a problem or something goes wrong?**
Tell us if there is a problem and we will try and sort it out straight away. You and your mum, dad or carer, or you can either contact the:

**Project co-ordinator:**
Nathalie Gray (Trainee Clinical Psychologist)
University of Leicester
104 Regent Road
Leicester
LE1 7LT
Email: nk204@le.ac.uk
Telephone: 0116 223 1639

Or the Patient Information and Liaison Service (PILS):
University Hospitals of Leicester
Patient Information and Liaison Service
The Firs
C/O Glenfield Hospital
Groby Road
Leicester
LE3 9QP

Email: pils@uhl-tr.nhs.uk

Freephone line: 08081 788337

(Monday to Friday 10am to 4pm)

Leicestershire Partnership NHS Trust
Patient Information and Liaison Service
Lakeside House
4 Smith Way
Grove Park
Enderby
Leicester
LE19 1SX

Email: PALS@leicspart.nhs.uk

0116 295 0830 (Monday to Friday 9am - 5pm)

**Will anyone else know I’m doing this?**

The people in our research team will know you are taking part. The treatment team helping you with your diabetes and coeliac disease will also know. All information that is collected about you during the research will be kept strictly confidential. You will be given a number which will be used instead.

Any information about you that leaves the hospital will have your name and address removed so that you cannot be recognised from it. Once the study is complete all information will kept for 5 years or after then it will be destroyed.
What will happen to the results of this study?
When the study has finished I will present the findings to other doctors, and we will put the results in medical and psychology magazines and websites that doctors read. Results will be anonymous, which means that you will not be able to be identified from them. I may use some sentences from my interviews with you. I will change names and places so that no-one should be able to work out that it was your sentence that I used. The results will also be included as part of my educational qualification.

Who is organising and funding the research?
Clinical Psychologists within the Paediatric Psychology Service and myself, a researcher at the University of Leicester are organising this study. They will not get any extra money for doing this research. The research is being paid for by the University of Leicester.

Who has checked the study?
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How can I find out more about research?
The University Hospitals of Leicester has information about research on its website:

http://www.leicestershospitals.nhs.uk/aboutus/education-and-research/

To find out more about research and development at Leicestershire Partnership NHS Trust please visit:

Thank you for taking the time to read this.

Any questions?
We would be really pleased if you decided to take part in this research. If you would like further information, you can contact us using the contact details in this leaflet.

If you would like to express an interest in taking part, please complete the slip on the bottom of the page, detach the slip along the dotted line, and return using the enclosed stamped addressed envelope.

Thank you!

---

**Expression of Interest**

**Young people’s experiences of living Type 1 Diabetes and Coeliac Disease**

I would like to express an interest in taking part in the research project exploring young people’s experiences of living with Type 1 Diabetes and Coeliac Disease. By providing my contact details below, I consent to being contacted by the researcher to discuss suitability and potential participation in the research project.

Name of Young Person: ____________________________________________

Name of Parent: _________________________________________________

Address: ________________________________________________________

Telephone number: ______________________________________________

Email: __________________________________________________________

PLEASE RETURN USING ENCLOSED SAE TO: Nathalie Gray, University of Leicester, 104 Regent Road, Leicester, LE1 7LT
Would you be interested in taking part in a research project exploring young people's experiences of living with Type 1 Diabetes and Coeliac Disease?

Part 1

Study Title

Young people’s experiences of living with Type 1 Diabetes and Coeliac Disease.

Invitation paragraph

Hello! We are inviting your child to take part in a research project about young people’s experiences of living with type 1 diabetes and coeliac disease. Before you decide if you would like your child to take part, it is important for you to understand why the research is being done and what you and your child will need to do to take part. This leaflet will tell you more.

Who are we?

My name is Nathalie Gray. I am a trainee clinical psychologist and a student at the University of Leicester. I am completing this research project as part of my training in clinical psychology. I am being supervised by Mrs Mary O’Reilly at the University of Leicester, and Dr Camilla Watters and Dr Amandeep Samrai who are Clinical Psychologists working in Leicester Partnership NHS Trust. My supervisors are there to make sure I am doing the project in the right way.

What is our research about?

We are hoping to find out about the experiences of young people like your child, who are with living with type 1 diabetes and coeliac disease. We are interested in hearing about
the time when your family was told about your child’s conditions, how your child feels about it, and how things are at home and school for your child now.

Why are we doing this research?
There is limited research in this area. Available research has looked at people’s experiences of living with type 1 diabetes or coeliac disease. However, there is very limited research on the experiences of young people living with both conditions. The aim of the proposed study is to look at young people’s experiences of adjusting and coping with both type 1 diabetes and coeliac disease; we want to understand what it is like for young people living both conditions. We also hope that the research will help us think about better ways that health professionals can support you in living with both conditions.

Why is your child being invited to take part?
Your child is being invited to take part because they are aged between 11 and 18 years and have a diagnosis of type 1 diabetes and coeliac disease. Unfortunately, we are not able to include children who have been diagnosed with both conditions for less than six months, or if English is not their first language. We are hoping to interview between approximately 10 young people in total.

Do we have to take part?
No. It is up to you and your child to decide if you want to take part. If you and your child do decide that your child would like to take part, I will give you this booklet to keep. I will also ask you and your child to sign a consent form. If you do agree to take part, your child can change their mind at any time, without giving a reason. This will not affect any care or support that your child or your family receive.

What will my child be doing if they do take part?
Your child will be invited to attend an interview at NHS sites such as the Leicester Royal Infirmary. It might also be possible for interviews to take place at home. I will be asking your child some general questions and your child will have the chance to talk about when your family were told about their diagnosis of type 1 diabetes and coeliac disease, and what kind of things they do every day. I will only ask short, general questions; your child will be able to say as much as they want. I will tape the sessions so that I can write down exactly what your child says, and exactly what I say. I will be looking for the patterns in
what young people say about their experiences. When I have typed up what we have
talked about, I will send you and your child the information so that your child can tell me
if they agree with it.

The interview should take between 1 hour to 1 ½ hours. You will asked to wait for your
child in the nearest waiting room if attending at an NHS site. I will ask you to leave a
contact number in case your child needs you at any time during the interview.

**Are there any advantages to taking part in the study?**
We are not offering any kind of treatment. However, if you and your child choose to take
part, your child will have a chance to help us understand what it is like for young people
living with both type 1 diabetes and coeliac disease. We hope that this research will be
published and make a difference to how young people are supported in managing both
conditions.

**What are the possible disadvantages?**
Your child may find the interviews distressing. We do not expect your child to talk about
times that were very upsetting for them and your child can end the interview at any time.
We will take your telephone number in case we need to contact you at any time during
the interview.

**Will there be any incentives / compensation for travel?**
Yes. We are offering every young person that takes part in the research a £10.00 Amazon
or ITunes Gift Card as a thank you for taking part. We will also pay your mileage/travel
costs. Travel costs can be claimed on the day of the interview.

**Contact for further information**
Nathalie Gray (Trainee Clinical Psychologist)  Email: nk204@le.ac.uk
Address: University of Leicester
104 Regent Road
Leicester
LE1 7LT
Telephone: 0116 223 1639
Camilla Watters (Consultant Clinical Psychologist)
Address: Department of Paediatric Psychology
c/o Westcotes House
Westcotes Drive
Leicester LE3 0QU
Telephone: 0116 295 2959

Thank you for reading so far - if you are still interested, please go to Part 2.

Part 2 more detail – information you need to know if you still want to take part:

Will the information be confidential?
All information that is collected will be anonymised. I will not disclose any information about you or your child (unless you give me permission). I will keep what your child has said during the research interview confidential. However information will not remain confidential if your child tells me that your child or someone else is being hurt, or is at risk of any kind of harm. If this is the case, I am obliged to disclose this to my supervisor, who will decide what we should do with the information.

How will my child’s information be stored and used?
All recorded interviews will be anonymised during transcription. All data will be held securely in accordance with the Data Protection Act (1998). Data generated by the study including transcripts of the interviews will be stored securely for a period of five years, after which it will be destroyed.

Can we change my mind about taking part?
Your child can change their mind about taking part at any time without giving a reason. This will not affect any care or treatment that they receive. If your child changes their
mind after they have completed the interview, you will need to let us know before 1st November 2015 so that we can remove their information from the study.

**What if there is a problem and I want to complain?**

Please tell us if there is a problem and we will try and sort it out straight away. You can either contact the:

**Project co-ordinator:**
Nathalie Gray (Trainee Clinical Psychologist)
University of Leicester
104 Regent Road
Leicester
LE1 7LT

Email: nk204@le.ac.uk
Telephone: 0116 223 1639

Or the **Patient Information and Liaison Service (PILS):**
University Hospitals of Leicester

**Patient Information and Liaison Service**
The Firs
C/O Glenfield Hospital
Groby Road
Leicester
LE3 9QP

Email: pils@uhl-tr.nhs.uk
Freephone line: 08081 788337
(Monday to Friday 10am to 4pm)

**Leicestershire Partnership NHS Trust**
Patient Information and Liaison Service
Lakeside House
4 Smith Way
Grove Park
Enderby
Leicester
LE19 1SX

Email: PALS@leicspart.nhs.uk
0116 295 0830 (Monday to Friday 9am-5pm)
Will anyone else know my child is taking part?
The people in our research team will know your child is taking part. The treatment team helping your child with your diabetes and coeliac disease will also know. All information that is collected about you during the research will be kept strictly confidential. Your child will be allocated a case number which will be used instead. Any information about your child that leaves the hospital will have the name and address removed so that they cannot be recognised from it. Once the study is complete all information will kept for 5 years or after then it will be destroyed.

What will happen to the results of this study?
I will write up what I have done as a research project as part of my thesis for a Doctorate in Clinical Psychology. We also hope that the research will be published in a journal that is interested in this topic area; I may use some sentences from my interviews with your child to explain the findings. All data will be anonymised; I will change all identifiable information such as names and places to maintain your child’s confidentiality. I will feedback a summary of the results to the teams involved in the research.

Who is organising and funding the research?
Clinical Psychologists within the Paediatric Psychology Service and myself, a researcher at the University of Leicester are organising this study. They will not get any extra money for doing this research. The research is being paid for by the University of Leicester.

Who has checked the study?
Before any research goes ahead it has to be checked by a Research Ethics Committee. This is a group of people who make sure that the research is OK to do. This study has been looked at by Northampton Research Ethics Committee. It has also been checked by the Research Department at the University of Leicester, Leicestershire Partnership NHS Trust, and University Hospitals of Leicester NHS Trust.

How can I find out more about research?
The University Hospitals of Leicester has information about research on its website:

http://www.leicestershospitals.nhs.uk/aboutus/education-and-research/
To find out more about research and development at Leicestershire Partnership NHS Trust please visit:


Thank you for taking the time to read this.

Any questions?
We would be really pleased if you decided to take part in this research. If you would like further information or you have any questions, you can contact us using the details provided in this information sheet.

If you would like to express an interest in taking part, please complete the slip below, detach the slip along the dotted line, and return using the enclosed stamped addressed envelope.

Thank you!

---

Expression of Interest

Young people’s experiences of living Type 1 Diabetes and Coeliac Disease

I’d like to express an interest in taking part in the research project exploring young people’s experiences of living with Type 1 Diabetes and Coeliac Disease. By providing my contact details below, I consent to being contacted by the researcher to discuss suitability and potential participation in the research project.

Name of Young Person: ________________________________
Name of Parent: ____________________________________
Address: __________________________________________
Telephone number: _________________________________
Email: ____________________________________________

I prefer to be contacted by (please tick)  □ Telephone  □ Email  □ Post

PLEASE RETURN USING ENCLOSED SAE TO: Nathalie Gray, University of Leicester, 104 Regent Road, Leicester, LE1 7LT
### Appendix K – Study inclusion and exclusion criteria

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Being under the care of paediatric psychology, diabetes or gastroenterology teams at the time of recruitment.</td>
<td>• Presenting with any cognitive impairments/difficulties.</td>
</tr>
<tr>
<td>• English as first language&lt;sup&gt;7&lt;/sup&gt;.</td>
<td>• Any potential and/or active risks identified at the time of recruitment e.g. experiencing high levels of distress.</td>
</tr>
<tr>
<td>• Young people aged 11-18 years.</td>
<td>• Severe and enduring mental health problems, such severe anxiety/low mood, significant self-harm/suicidal ideation, psychosis, and eating disorders requiring specialist treatment.</td>
</tr>
<tr>
<td>• A diagnosis of both Type 1 Diabetes and Coeliac Disease for six months or more.</td>
<td></td>
</tr>
</tbody>
</table>

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<sup>7</sup> Inclusion criteria should have stated ‘fluent in English’ rather than ‘English as first language.’ Of note, no participants fluent in English were excluded from the study.
Appendix L - Topic Guide

Topic Guide

- Start with experience of diagnoses of a) type 1 diabetes and b) coeliac disease.

  Possible prompts:
  - How old were you when you were told that you have diabetes/coeliac disease?
  - What symptoms did you have?
  - Who told you about it?
  - What did you think?
  - How did you feel then?
  - Who was with you at the time?
  - What did they think?

- Self-management of diabetes and coeliac disease.

  Possible prompts:
  - What do you do to manage your diabetes? (monitoring, injecting, planning meals etc.)
  - What do you do to manage your coeliac disease?
  - Do you tend to manage one of the conditions more than the other?
  - How do other people help you manage the conditions (e.g. parents, family members, friends)?
  - How does this make you feel?
  - Who helps you the most?
  - Who helps you the least?

- Changes at home since diagnosis of diabetes and coeliac disease.

  Possible prompts:
  - Is there anything you used to do, that you don’t do anymore?
  - Is there anything you do more than you used to?
  - What changes have you had to make to your diet and eating?
  - How has the diabetes and coeliac disease affected your health?
  - Have your relationships changed with friends?
  - Have your relationships changed with family?
  - What is it like being away from home (e.g. family outings/events/holidays)?
  - How do you feel about these changes?
  - Has the diabetes and coeliac disease affected how you feel about yourself?
  - How would you like things to be different at home?

- Changes at school since diagnosis of diabetes and coeliac disease.

  Possible prompts:
  - What is it like being at school?
  - What is difficult about being at school?
  - How do you manage these difficulties?
  - Who helps you with managing the diabetes and coeliac disease at school?
  - Does anyone make managing the diabetes and coeliac disease difficult for you at school?
  - How would you like things to be different at school?

- Explaining to other people about having diabetes and coeliac disease.
Possible prompts:

- Who do you tell?
  - Friends?
  - Teachers?
  - People in restaurants, canteens?
  - Anyone else?
  - How do you explain it to others?
  - How do they respond when you tell them?
  - How you feel about that?
  - Is there anyone that you avoid talking about diabetes and coeliac disease?
  - How do you decide this?

• How other people might feel about diabetes and coeliac disease.

Possible prompts:

  - Parents?
  - Friends?
  - Family?
  - Teachers?
  - Others?

• Coping with having both diabetes and coeliac disease.

Possible prompts:

  - What makes it harder to live with diabetes and coeliac disease?
  - What makes it easier for you?
  - What worries you the most about having diabetes and coeliac disease?
  - What worries you the least?
  - Are there any times where you don’t mind having diabetes and coeliac disease?
  - What would you say to other young people who have diabetes and coeliac disease?

• Help and support from healthcare professionals?

Possible prompts:

  - Who is involved in your care?
  - How often do you see them?
  - What do they help you with?
  - What is helpful about the support they give you?
  - What is not so good about the support they give you?
  - How would you like things to be different?
Appendix M – Confidentiality Agreement

The British Psychological Society has published a set of guidelines on ethical principles for conducting research. One of these principles concerns maintaining the confidentiality of information obtained from participants during an investigation.

As a transcriber you have access to material obtained from research participants. In concordance with the BPS ethical guidelines, the Doctorate in Clinical Psychology Research Committee requires that you sign this Confidentiality Statement for every project in which you act as transcriber.

General

- I understand that the material I am transcribing is confidential.
- The material transcribed will be discussed with no-one.
- The identity of research participants will not be divulged.

Transcription Procedure

- Transcription will be conducted in such a way that the confidentiality of the material is maintained.
- I will ensure that audio-recordings cannot be overheard and that transcripts, or parts of transcripts, are not read by people without official right of access.
- All materials relating to transcription will be returned to the researcher.

Signed ___________________________ Date 15-9-16
Print Name ___________________________
Researcher Nathalie Gray (Trainee Clinical Psychologist)
Project Title Young People’s Experiences of Type 1 Diabetes and Coeliac Disease.
Appendix N - An example of initial coding

Extract taken from Sarah, Lines 273-280.

<table>
<thead>
<tr>
<th>Initial line by line coding</th>
<th>Transcript Extract</th>
</tr>
</thead>
<tbody>
<tr>
<td>Routines are helpful</td>
<td>Um I have sort of set routines I think which are quite helpful. I make sure that if I’m going out I have everything that I need so that I’ll be OK. Um I do everything myself from quite a young, from like the very beginning, which makes me feel like I can do it myself which stops me feeling sort of. And just trying not to sort of like trying to have good control of my diabetes and what I’m eating myself. So that I’m not sort of feeling like I can’t do anything about it and I’m going to just get ill. Make sure that I’m staying really really healthy. Make sure I have good control of my diabetes and my coeliac disease. I think. Yeah.</td>
</tr>
<tr>
<td>Preparing to go out</td>
<td></td>
</tr>
<tr>
<td>Being equipped</td>
<td></td>
</tr>
<tr>
<td>Independent</td>
<td></td>
</tr>
<tr>
<td>Taking responsibility from</td>
<td></td>
</tr>
<tr>
<td>the beginning</td>
<td></td>
</tr>
<tr>
<td>Feeling in control</td>
<td></td>
</tr>
<tr>
<td>Control over diabetes</td>
<td></td>
</tr>
<tr>
<td>Control over diet</td>
<td></td>
</tr>
<tr>
<td>Preventing illness</td>
<td></td>
</tr>
<tr>
<td>Staying healthy</td>
<td></td>
</tr>
<tr>
<td>Feeling in control</td>
<td></td>
</tr>
</tbody>
</table>
Appendix O - An example of focussed coding

Extract taken from Sarah, Lines 273-280.

<table>
<thead>
<tr>
<th>Focussed codes</th>
<th>Transcript Extract</th>
</tr>
</thead>
<tbody>
<tr>
<td>Structured routines</td>
<td>Um I have sort of set routines I think which are quite helpful. I make sure that if I’m going out I have everything that I need so that I’ll be OK. Um I do everything myself from quite a young, from like the very beginning, which makes me feel like I can do it myself which stops me feeling sort of. And just trying not to sort of like trying to have good control of my diabetes and what I’m eating myself. So that I’m not sort of feeling like I can’t do anything about it and I’m going to just get ill. Make sure that I’m staying really really healthy. Make sure I have good control of my diabetes and my coeliac disease. I think. Yeah.</td>
</tr>
<tr>
<td>Being prepared</td>
<td></td>
</tr>
<tr>
<td>Developing independence</td>
<td></td>
</tr>
<tr>
<td>Need for control</td>
<td></td>
</tr>
<tr>
<td>Staying healthy</td>
<td></td>
</tr>
<tr>
<td>Need for control</td>
<td></td>
</tr>
</tbody>
</table>
Appendix P – An example of memo writing

Extract from the research journal

<table>
<thead>
<tr>
<th>Interview 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have read through my first interview with Ben a few times and the following things jump out at me:</td>
</tr>
<tr>
<td>- The amount of knowledge this young person has about diabetes and coeliac disease</td>
</tr>
<tr>
<td>- The level of detail in his explanations</td>
</tr>
<tr>
<td>- How keen he is to share his experiences with me</td>
</tr>
<tr>
<td>- His positive view of gluten free food</td>
</tr>
<tr>
<td>- His level of self-control and discipline with food and his use of routines to support this</td>
</tr>
<tr>
<td>- The amount of planning and preparation he has to think about at his age.</td>
</tr>
</tbody>
</table>

I have started line by line coding the transcript. I am reading through the text and then jotting down my line-by-line codes in the margin. I am finding it quite difficult to develop succinct codes and I feel that I’m just re-writing the words of the participant. However on balance by using the same words, I can see that this allows be to stay ‘close’ to the data. I am also aware of Charmaz (2006) advice about using gerunds, or doing words, to be alert to the processes that are happening in the text. I am finding this helpful.

I am now feeling quite overwhelmed with the amount of data the open coding has generated. I am reading back through the open codes and looking for patterns and processes emerging in these codes. I am hoping that this will help me develop more focussed codes, codes that will narrow down concepts in the data. I am writing the focussed codes in a different coloured pen in the margin, near the open codes they relate to. I am going to type up these focussed codes in a word document to keep track of them. This process has generated a total of 45 codes which I feel is a lot. However I’m sure (and hope!) that as I go through the process of analysis the codes will become more refined. I was unsure whether to spend the time grouping together these focussed codes and putting them into categories at this stage. However just because of the
amount of codes I think that’s the only way I’m going to be able to keep track of patterns in the data, which I’m hoping will facilitate the process of analysing subsequent interviews.

I have grouped the focussed codes into the following categories:

1. Responses to diagnoses
2. Developing knowledge
3. Practical strategies
4. Developing independence
5. Responses to gluten free food
6. Family relationships
7. Relationships with friends
8. Managing social situations
9. Professional support

I have started to tentatively describe and define these categories. Extracts from the interviews will be used as evidence to demonstrate and support the category. The categories so far seem quite descriptive but I think this is OK. These categories are tentative at this stage after only one interview. I imagine that they will go through a number of transformations before I get to the final product or model. After completing this process of developing codes and initial categories, there are themes in this transcript that have left me with more questions:

- How do other participants’ family members view gluten free food?
- Do other people in the family have coeliac or diabetes? How does this impact on participants?
- How do participant’s view themselves in relation to their conditions?

I hope to explore this in the next interview.
Appendix Q - An example of a memo on forming categories

Memo on the ‘Family Relationships’ category after Interview 1 (Ben)

Focussed codes:
- Clear roles in the family
- Family responses to gluten-free food

Ben describes himself as very independent in the management of his conditions, he appears to minimise the support his family give him. I wonder if this links in with his need to be recognised as independent by others and also by me during the interview. Ben describes his parents as supportive and that they had clear roles of communicating with school and friends parent’s, supporting him to arrange and attend appointments, providing him with gluten-free food and supplies he needs to manage his conditions, and also providing support with diabetes tasks when he needs it. It appeared to me that his family culture around diabetes and coeliac disease may have contributed to and facilitated his sense of independence which are clearly very important for Ben.

Ben: People have helped me by.. just. I'm actually pretty independent on it.. most of the time but.. if I'm drowsy-ish.. such as when I've just been woken up from my sleep.. just have a blood test.. my mum will just fetch me the glucotabs or.. or something like uh.. coffee with sugar in it.. just so it can get me up quickly.

Ben described also how his family have very positive views of the GFD such as it being better quality and describing a range of positive tastes and textures.

Ben: My family's probably thinking I’m rather lucky with the fact that I get some of the best stuff of the food shop.

Interviewer: OK. So what do they think about gluten free food?

Ben: They do think it's a lot more quality than gluten food. I've heard them say this numerous times, again and again.

Interviewer: So when you say 'more quality' what do you mean?

Ben: More taste, instead of a, so less of a bland taste, more of an exuberant and exotic and more filling tastes. Mind you, gluten free is also got a giant range of rich foods, such as that chocolate log. I could imagine this.. I could.. I have found a lot of.. some of the cakes can be really rich. And really heavy.

Interviewer: Do your family like gluten free food?

Ben: They've tried and they love it.

Positive family views appeared to promote a positive relationship with gluten free food for Ben.
Appendix R - An example of a memo on merging categories

I attended the qualitative research group yesterday. I took my categories along and explained them to a fellow trainee. During discussions it became really apparent that ‘developing independence’ and ‘how I think about diabetes and coeliac disease’ were closely related.

I had thought about the function of independence earlier on in my analysis however I resisted an urge to amend it. One of the challenges I have encountered in the analysis is managing large amounts of data and moving from descriptive to analytical in my categories. I also need to maintain a focus on my research question and aims of the study. My aim is to explain how participants managed their diagnoses of diabetes and coeliac disease. I felt a little bit attached to the ‘developing independence’ category as it seemed so important for participants, however I can see that participants were very much using their sense of independence as a psychological strategy to gain control over their management of diabetes and coeliac disease. This was very apparent in my explanation to my colleague about this category.

We also talked about how the different strategies could be merged under the larger category of ‘how I think about diabetes and coeliac disease’.
Appendix S – Confirmation of Ethical Approval

30 April 2015

Mrs Nathalie Gray
University of Leicester
School of Psychology
104 Regent Road
Leicester
LE1 7LT

Dear Mrs Gray,

| Study title: | Young people’s experiences of living with a diagnosis of Type 1 Diabetes and Coeliac Disease: a grounded theory approach. |
| REC reference: | 15/EM/0136 |
| Protocol number: | 2 |
| IRAS project ID: | 162675 |

Thank you for your letter of 26 April 2015, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Rebecca Morledge, NRESCommitteeEastMidlands-Northampton@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.
Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission (“R&D approval”) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites (“participant identification centre”), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion” below).
Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Copies of advertisement materials for research participants [Research Foster]</td>
<td>2</td>
<td>26 April 2015</td>
</tr>
<tr>
<td>Interview schedules or topic guides for participants [Interview Topic Guide]</td>
<td>2</td>
<td>25 February 2015</td>
</tr>
<tr>
<td>IRAS Checklist XML [Checklist_26042015]</td>
<td></td>
<td>29 April 2015</td>
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<tr>
<td>IRAS Checklist XML [Checklist_30042015]</td>
<td></td>
<td>30 April 2015</td>
</tr>
<tr>
<td>Letters of invitation to participant [Letter of Invitation]</td>
<td>1</td>
<td>26 April 2015</td>
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<tr>
<td>Other [Parent Information Sheet]</td>
<td>3</td>
<td>26 April 2015</td>
</tr>
<tr>
<td>Other [Young Person Consent Form]</td>
<td>3</td>
<td>26 April 2015</td>
</tr>
<tr>
<td>Other [Parent Consent Form]</td>
<td>3</td>
<td>26 April 2015</td>
</tr>
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<td>Other [Letter of Invitation 16-18 years]</td>
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<td>Other [Response Letter to Mr John Aldridge]</td>
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<td>Other [Young Person 16-18 years Information Sheet]</td>
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<tr>
<td>Participant consent form [Young Person Assent Form]</td>
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<td>26 April 2015</td>
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<tr>
<td>Participant information sheet (PIS) [Young Person Information Sheet]</td>
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<tr>
<td>REC Application Form [REC_Form_06032015]</td>
<td></td>
<td>06 March 2015</td>
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<tr>
<td>Research protocol or project proposal [Research Protocol]</td>
<td>2</td>
<td>16 February 2015</td>
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<tr>
<td>Summary CV for Chief Investigator (Ci) [NG CV]</td>
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<td>15 February 2015</td>
</tr>
<tr>
<td>Summary CV for supervisor (student research) [MO CV]</td>
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Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.
User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

15/EM/0136 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely,

Mr John Aldridge
Chair

Email: NRESCommittee.EastMidlands-Northampton@nhs.net

Enclosures: “After ethical review – guidance for researchers”

Copy to: Mr. David Clarke
Appendix T – Participant Consent Form (11-15 years)

Young Person (11-15 Years) Consent Form

Young people's experiences of living with Type 1 Diabetes and Coeliac Disease

Please INITIAL the box if you agree with the statements below:

I have read the information leaflet (v3 26.04.2015) about the project

☐

Nathalie has explained the project to me

☐

I have had the chance to ask questions about the project

☐

I know all the answers to my questions

☐

I know what the project is about

☐

I know that I can change my mind about taking part at any time

☐

I know that my interview will be recorded and that some of what I say might be written in the final report. Any information that might let other people know who I am will be changed or removed.

☐

I want to take part in this research project

☐

Please sign* here if you have marked all of the boxes above.

Name: _____________________________________________________

Signature: ________________________________________________

Date: _____________________________________________________
If you are under 16 years old your parent or guardian must also sign to say they are happy for you to take part in the project.

I confirm that I am happy for my child to be involved in the research study.

Name (Parent 1):________________________________________________________
Signature: ______________________ Date: __________________

Name (Parent 2):________________________________________________________
Signature: ______________________ Date: __________________

To be completed by the researcher:

The participant has been provided with an information sheet and I have explained the project to them. He/she has indicated his/her willingness to participate.

Name: __________________________________________________________________
Signature________________________ Date: __________________
Appendix U – Participant Information Sheet (16-18 years)

Young Person (16-18 Years) Consent Form

Young people's experiences of living with
Type 1 Diabetes and Coeliac Disease

Please INITIAL the box if you agree with the statements below:

I have read the information leaflet (v3 26.04.2015) about the project

The project has been explained to me by the researcher

I have had the opportunity to ask questions about the project

I am happy with the answers to my questions

I understand what the project is about

I understand that I can change my mind about taking part at any time

I understand that the interview will be recorded and that some of what is said might be written in the final report. However all data will be anonymised; identifiable data will be changed or removed.

I want to take part in this research project

Please sign here if you agree with the all statements above.

Name: ____________________________

Signature: ____________________________ Date: ____________________________

To be completed by the researcher:

The participant has been provided with an information sheet and I have explained the project to them. He/she has indicated his/her willingness to participate.

Name: ____________________________

Signature: ____________________________ Date: ____________________________
Appendix V – Parent Consent Form

Parent Consent Form

Young people's experiences of living with Type 1 Diabetes and Coeliac Disease

Please tick the box if you agree with the statements below:

I have read the information leaflet (v3 26.04.2015) about the project
The project has been explained to me by the researcher
I have had the opportunity to ask questions about the project
I am happy with the answers to my questions
I understand what the project is about
I understand that I can change my mind about my child taking part
I understand that the interview will be recorded and that some of what is said might be written in the final report. However all data will be anonymised; identifiable data will be changed or removed.
I am happy for my child to take part in this project

Please sign here if you give consent for your child to take part and have ticked all of the boxes above.

Parent 1 Name: ________________________________________________
Signature: ______________________________________________________
Date: __________________________________________________________________

Parent 2 Name: ________________________________________________
Signature: ______________________________________________________
Date: __________________________________________________________________
To be completed by the researcher:

The participant has been provided with an information sheet and I have explained the project to them. He/she has indicated his/her willingness to participate.

Name: _____________________________________________________________

Signature: _________________________ Date: ___________________________